

Understanding the role of care staff in supporting individuals with an intellectual disability who take psychotropic medication

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ABSTRACT

Intellectual disability services are under constant change with *Transforming Care* being the latest UK policy aimed to improve services. The *STOMP* agenda forms part of this, as a call to action against the overmedication of people with intellectual disabilities. Recent service policy has come about following exposés of scandals where support workers have been found to be abusing the people they are paid to support. Despite these findings and the intimate role support workers have with people with intellectual disability, there is a paucity of research to understand this unique role. In response, this study aimed to develop a model that could conceptualise the role of support workers in caring for people with intellectual disability that take psychotropic medication. Constructivist grounded theory from a pragmatist position, which complements the research aim and questions of this study was carried out. The “negotiating dis/ability” model was constructed using interview data from support workers who had experience of working with people with intellectual disability who take psychotropic medication. “Disablement” and “ablement” were dominant processes for support workers negotiating a (medication) role in their relationships with others in the system. Support worker’s “dis/ablement” was constructed of a broader ableism that permeates throughout intellectual disability services. This study demonstrated how current interventions “disable” others through individualising problems within the support worker as well as the person with intellectual disability; taking a radical systemic approach may help to counter these narratives and lead to better outcomes, including more successful medication reductions.

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To my wife and daughter, you mean everything to me. I couldn't have done it without you.

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CONTENTS

1 INTRODUCTION.....	7
1.1 DEFINING INTELLECTUAL DISABILITY	7
1.1.1 HISTORY OF PEOPLE WITH INTELLECTUAL DISABILITY.....	8
1.1.2 EARLY DEFINITIONS AND ASSESSMENT OF INTELLECTUAL DISABILITY.....	10
1.1.3 CURRENT ASSESSMENT AND DEFINITIONS	11
1.1.4 CRITICISMS OF THE INTELLIGENCE TEST	12
1.1.5 REDEFINING DISABILITY.....	13
1.2 TOWARDS A ‘NORMALISED’ LIFE.....	15
1.2.1 THE NORMALISATION REVELATION	15
1.2.2 CRITIQUES OF NORMALISATION	16
1.2.3 NORMALISATION IN POLICY	17
1.2.4 POST-NORMALISATION	18
1.3 USE OF PSYCHOTROPIC MEDICATION	19
1.3.1 THE MEDICATING OF PEOPLE WITH INTELLECTUAL DISABILITY	20
1.3.2 EFFICACY OF MEDICATION	21
1.3.3 CURRENT PRACTICE	22
1.3.4 THE CURRENT ALTERNATIVE TO MEDICATION	23
1.3.5 STOPPING THE OVER-MEDICATION OF PEOPLE WITH LEARNING DISABILITIES, AUTISM OR BOTH (STOMP)	24
1.4 THE ROLE OF CARE (SUPPORT) WORKERS.....	26
1.4.1 CARE WORKERS AS AN UNDERPRIVILEGED WORKFORCE.....	26
1.4.2 WELLBEING AND SUPPORT FOR CARE WORKERS	28
1.4.3 CARE WORKERS IN THE LITERATURE	29
1.5 CURRENT POSITION OF SERVICE FOR PEOPLE WITH INTELLECTUAL DISABILITIES	31
1.6 RESEARCH AIM AND QUESTIONS	31
1.6.1 RESEARCH AIM	32
1.6.2 RESEARCH QUESTIONS.....	32
2. METHOD.....	32
2.1. OVERVIEW	32
2.2 PRAGMATISM AS A RESEARCH PARADIGM	33
2.2.1 PRAGMATISM ON TERMINOLOGY	34

2.3 CONSTRUCTIVIST GROUNDED THEORY	34
2.3.1 THE EMERGENCE OF GROUNDED THEORY	35
2.3.2 KEY COMPONENTS OF CONSTRUCTIVIST GROUNDED THEORY	36
2.4 A PRAGMATIC APPROACH TO CONSTRUCTIVIST GROUNDED THEORY	37
2.5 ETHICAL CONSIDERATIONS	38
2.5.1 PARTICIPANTS AND THE PEOPLE THEY SUPPORT	38
2.5.2 ETHICS PROCEDURE	39
2.6 DESIGN	40
2.7 PROCEDURE	40
2.7.1 INITIAL GROUNDWORK.....	40
2.7.2 SAMPLING.....	41
2.7.3 INCLUSION CRITERIA	42
2.7.4 PARTICIPANT DEMOGRAPHICS	42
2.7.5 INTERVIEWING.....	43
2.7.6 DATA ANALYSIS.....	43
2.8 ENSURING RIGOUR.....	44
 <u>3. ANALYSIS</u>	 <u>45</u>
 3.1 OVERVIEW	 45
3.2 A CONSTRUCTED GROUNDED THEORY MODEL: NEGOTIATING THE PSYCHOTROPIC MEDICATION ROLE OF SUPPORT WORKERS FOR PEOPLE WITH INTELLECTUAL DISABILITY ..	46
3.3 NEGOTIATING THE MEDICATION PRESCRIPTION ROLE WITH PSYCHIATRY.....	48
3.3.1 FEELING “DISABLED” IN PRESCRIPTION ROLE	49
3.3.2 FEELING “ABLED” IN PRESCRIPTION ROLE	55
3.4 NEGOTIATING MEDICATION PROCEDURE ROLE WITH PROVIDER MANAGERS	58
3.4.1 FEELING “DISABLED” IN MEDICATION PROCEDURES ROLE.....	59
3.4.2 FEELING “ABLED” IN PROCEDURES ROLE.....	65
3.5 NEGOTIATING THE CAREGIVER ROLE WITH PEOPLE WITH INTELLECTUAL DISABILITY ...	69
3.5.1 FEELING “DISABLED” IN CAREGIVING ROLE	70
3.5.2 FEELING “ABLED” IN ADMINISTRATION ROLE	73
3.6 SUMMARY OF ANALYSIS	76
 <u>4. DISCUSSION</u>	 <u>77</u>
 4.1 OVERVIEW	 77
4.2 INTERPRETATION OF THE MODEL, IMPLICATIONS AND RECOMMENDATIONS	78
4.2.1 PLACING THE MODEL IN THE CONTEXT OF EXISTING LITERATURE.....	78

4.2.2 SUPPORT WORKER “DIS/ABLEMENT”	79
4.2.3 TOP DOWN “DIS/ABLEMENT”	79
4.2.4 BOTTOM UP “DIS/ABLEMENT”	80
4.2.5 “DIS/ABLEING” ROLES AND RELATIONSHIPS	81
4.2.6 IMPLICATIONS FOR PSYCHOTROPIC MEDICATION USAGE IN SERVICES.....	84
4.2.7 RECOMMENDATIONS, TOWARDS A POST-NORMALISATION FUTURE	86
4.3 CRITICAL REVIEW OF RESEARCH	87
4.3.1 MEDICINE AS THE ONLY POWER?.....	87
4.3.2 SCRUTINISING RESEARCH AIM	88
4.3.3 EVALUATING THE GROUNDED THEORY METHOD	90
4.4 REFLEXIVE ACCOUNT	93
4.4.1 THE NON-NEUTRAL RESEARCHER	93
4.4.2 THE NON-NEUTRAL RESEARCH	94
4.5 CONCLUSION	95
<u>5 REFERENCES.....</u>	<u>97</u>
<u>6. APPENDICIES.....</u>	<u>127</u>
APPENDIX 1: UNIVERSITY OF EAST LONDON ETHICAL APPROVAL.....	127
APPENDIX 2: ADVERT TO RECRUIT PARTICIPANTS	130
APPENDIX 3: INFORMATION SHEET FOR PARTICIPANTS.....	131
APPENDIX 4: CONSENT FORM FOR PARTICIPANTS	134
APPENDIX 5: INTERVIEW SCHEDULE	135
APPENDIX 6: EXAMPLE OF THEORETICAL SAMPLING	137
APPENDIX 7: EXCERPT FROM MEMO FOLLOWING RAISING OF INITIAL CODES TO FOCUSED CODES	138
APPENDIX 8: EXAMPLES OF INITIAL CODING SHOWING THE LINE-BY-LINE APPROACH AND FOCUSSED CODING THAT FOLLOWS.....	139
APPENDIX 9: EXCERPT FROM MEMO DURING THE CONSTRUCTION OF CATEGORIES	144
APPENDIX 10: CATEGORIES AND THE FOCUSSED CODES THAT CONSTRUCT THEM IN THE FINAL MODEL	145
APPENDIX 11: DEVELOPMENT OF THE MODEL, SITUATIONAL MAPPING	150
APPENDIX 12: EXAMPLE OF NEGATIVE CASE ANALYSIS.....	152
APPENDIX 13: REFLECTIVE DIARY ENTRY EXAMPLE	154
APPENDIX 14: CONVENTIONS USED IN TRANSCRIBING AUDIO DATA.....	155

1 INTRODUCTION

This research will construct a model of supporting individuals with an intellectual disability¹ (ID) who take psychotropic medication as experienced by care workers (known as support workers in the ID sector).

The history of the term “intellectual disability” will be reviewed in its socio-political context and how this construction has changed over time with the subsequent impact on how ID diagnosis is understood and how people with this diagnosis are treated by society and organisations.

A review of the knowledge of psychotropic medication usage in people with ID will be provided including exploration of the processes involved in psychotropic medication for this population. Knowledge will be evaluated on the basis of who this has been useful for and what actions have resulted from it.

The unique context of support workers for people with ID will be outlined and the relevance of this role to ID and psychotropic medication, with particular reference to psychotropic medication reductions. Relevant policy, directives and guidelines will be set out and how this may impact on people with ID and those that support them.

Aim and research questions will conclude this chapter.

1.1 Defining intellectual disability

This section will review how the term “intellectual disability” used in current practice has a social and historical context that has constructed its use today, by understanding how people with ID have been labelled and treated in different

¹ The more commonly known term “learning disability” has different meanings in US literature compared to the UK and Commonwealth. Throughout this proposal, the internationally agreed term of “intellectual disability” will be used to avoid confusion (see BILD, 2019)

way is essential to understanding the utility of this concept and to whom it benefits.

1.1.1 History of people with intellectual disability

The term “learning disability” was only popularised in the UK in the 1990’s following the Community Care Act (Holland, 2011), before then a host of other labels were used to understand a group of people who throughout history may have their differences conceptualised in a very different way today.

Historically, the term “idiot” was used to describe people who were deemed to be “without sense”, thought to arise from the Greek word ‘*idiotes*’ meaning a common man. In English language, “idiot” remained in use up until the mid-20th century where the word became more diluted and generic in its meaning (Scull, 1979).

The Poor Act 1601 was a significant point in time for people with ID. Local parishes had the responsibility of providing accommodation for people who were described as the “impotent poor”, meaning individuals who could not work for a variety of reasons, largely due to illness. There was much debate around who could be considered the “deserving poor” and therefore eligible for support. As the industrial revolution of the 18th Century changed Britain’s landscape, so did socio-cultural attitudes towards those who did not work. Progress of a nation was associated with work and therefore the worth of a human was in the work they could produce (Carnaby, 2018; Scull, 1979).

Throughout the 19th century, involvement of the professional class for people with ID was largely competed for between medicine and educational reformists resulting in two conflicting approaches, to segregate or to normalise. There was much overlap though, between medicine and educational reform; where medicine had provided the explanation of “idiocy”, educational interventions could contribute to treatment. In fact many of the reformists were themselves physicians including one of the most prominent French reformists, Edouard Séguin who was committed to showing “idiots” as educable (Séguin, 1846, 1866). In the UK, the psychiatrist George Shuttleworth, who greatly admired Séguin’s work, was also a proponent of reform. He quotes another French

reformist, Esquirol, in aiming for “the removal of the mark of the beast, from the forehead of the idiot” (Shuttleworth, 1895 p. 1) and called for physicians and teachers to work hand-in-hand (Shuttleworth, 1895). His intention may have been honourable, but the socio-cultural hegemony of the time was focused strongly towards assimilation and not difference, as labour and the family would undergo seismic changes.

As the industrial revolution continued and the working life of people became encapsulated within a highly structured, factory-based regime, people with ID and others who did not fit into this style of work could no longer be supported by their families, statutory provisions licenced by the state therefore began to appear (Carnaby, 2018). Asylums were originally built in large numbers as a means to create an environment that could help people back into the community. Over the years however, social attitudes of the time and increasing numbers of people struggling to get by saw a mass overcrowding of asylums, where “treatment” failure meant no one left and educationalists’ behaviour turned from reform to control (Ryan & Thomas, 1987). Separated from the community, narratives about people who differed from the rest of society were reinforced as removable, creating a troubling precedent of attributing a clinical conceptualisation of those who act differently to the majority (Cromby, Harper, & Reavey, 2013).

Throughout the 20th Century, the concept of eugenics arose, which sought to develop human progress through eliminating defective genes from subsequent populations. Coined “Social Darwinism”, this movement sought to build structures and concepts to define whose genetic make-up would be deemed unfit for the next generation. Intelligence testing is largely thought to have developed from this movement due to the IQ testing of the US military purporting the idea that intellect is entirely heritable (Hawkins, 1997).

A number of legislative decisions were made regarding people with ID that reified not only the desire to treat ID as an illness but see them as a group that must be restricted by the state (Carnaby, 2018). The normalising of eugenics as applied to people with ID is clear when in 1910, the Home Secretary of the UK, Winston Churchill, called for the sterilisation of people with ID. Churchill was

drawn to the Indiana Reformatory in the USA, where various states had enforced the sterilisation of the “feeble minded” and others judged mentally unfit (Gilbert, 2009). If it wasn’t for Chief Medical Advisor, Horatio Donkin claiming the Indiana Reformatory as a “monument of ignorance” (HO, 1910) to Churchill, sterilisation may have been enacted. Despite strong advocacy for sterilisation, the Mental Deficiency Act 1913 only allowed enforcement of separation and treatment. The concept of mental deficiency had largely been accepted as scientifically explainable, inheritable condition. With this certitude, theories and assessments to conceptualise this developed, many of which have survived in various forms today.

1.1.2 Early definitions and assessment of Intellectual Disability

As the reformist movements started to house and intervene in the lives of people who did not fit in with the expectations of their local communities, the practice of categorising on what basis they were in “need” of the asylum also developed (Carnaby, 2018). The passing of the Mental Deficiencies Act 1913 enshrining in law the categorising of mentally deficient individuals into three groups; *Idiot*, *Imbecile* and *Feeble Minded*, with the latter being those seen as most “able”, and according to the Act, “trainable”.

In 1905, Alfred Binet and Théodore Simon had developed a measure for identified children who were “just below normal” in order to provide an educational, rather than an asylum based, intervention. Meanwhile, Eduoard Goddard, a eugenicist who operated in a US institution for “feeble minded” boys and girls (Gould, 1996), tried to prove the heritability of feeble mindedness using the Kallikak family (see Figure 1) as participants (Goddard 1912). He translated Binet’s IQ test and sought for its application to the general population despite Binet’s commitment against it being a measure of intelligence (Gould, 1996). It was Goddard’s commitment to the hereditary linkage of mental deficiency and his belief in its determination through IQ testing that has shaped the assessment of ID over the past 100 years.

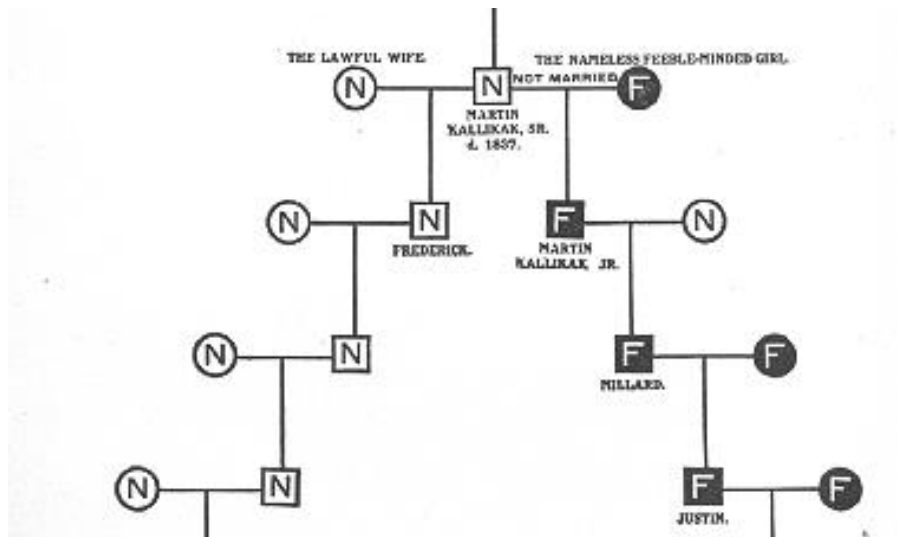


Figure 1: Genogram's claiming the heritability of "feeble mindedness" *adapted from* Goddard (1912 p.36) [N depicting "normal" and F "feeble minded"].

1.1.3 Current assessment and definitions

Since the implementation of the Stanford-Binet intelligence scales, the understanding of ID has been dominated by a neuropsychological/cognitive approach. It is conceptualised as a developmental disorder by both major classification systems (ICD-11 and DSM-V), where intellectual ability is significantly affected during the developmental period (APA, 2013; WHO, 2018).

This functional limitations or medical model of disability encapsulates this understanding, where a disability of intellect resides within the bio-psychological functioning of the individual (Danforth, 2001; Whittuck, 2014). The medical model of disability has its roots in the World Health Organisation's framework that marked out three main areas of impairment due to an underlying disease or disorder.

1. Impairment: Marked by a loss of typical functioning
2. Disability: Marked by any limitation that impacts on typical performance
3. Handicap: The resulting disadvantage compared to peers due to an impairment or disability (WHO, 1980)

Given the historical and current conceptualisation of ID as a difficulty that resides within the mind or brain of individuals affected, it is perhaps not surprising that assessment and diagnosis is the domain of what it known as the

“psy-professions” (Whittuck, 2014 p. 120), namely psychologists who measure cognition and behaviour as a reflection of this underlying impairment.

Currently, clinical psychologists are the main gatekeepers to UK adult ID services given their expert position over cognitive testing. The British Psychological Society’s Division of Clinical Psychology (DCP) sets out guidance on the assessment and diagnosis of ID. In order for a diagnosis of ID to be met, significant impairment must be found in intellectual and adaptive functioning with these impairments being present before the age of 18 (DCP, 2015). In fitting with historical testing, categorisation of ID still occurs, this is divided into 4 main subtypes based on mild, moderate, severe or profound support needs (AAIDD, 2010; WHO, 2018) as identified in adaptive behaviour measures and independent functioning.

1.1.4 Criticisms of the intelligence test

The scientific usefulness of an ID construct is debatable; the primary method of assessing for ID is by using a type of cognitive assessment that is regarded to measure intelligence. In UK ID services, this is usually the *Wechsler Adult Intelligence Scales (WAIS)* currently in its fourth edition (Wechsler, Coalson, & Raiford, 2008). This is an individually administered test of a person’s intellectual ability and cognitive strengths and weaknesses, the WAIS-IV consists of core subtests that are grouped into four domains of ability across verbal and non-verbal reasoning, working memory, and speed of psychomotor processing. A “Full-Scale IQ” score is calculated, which is matched against population norms to determine likelihood of an ID, anything marked below 70 (two standard deviations below the norm) is considered to be evidence of an ID unless measures of adaptive behaviour greatly contradict this or the difficulties arose after 18 years old (Brue & Wilmshurst, 2016).

Much analysis of the WAIS has been undertaken by psychologist, Simon Whitaker. Whitaker has produced a number of papers critiquing the reliability and validity of intelligent tests (2005, 2013a, 2013c, 2015b, 2015a). He argues that “cut off” points for such a diagnosis are not justified. Cut offs mean marking a point in an assessment where impairment or difference from the norm is considered to be of clinical or diagnostic significance. There is however now

clear representation that a cut-off point represents a significantly different ability to cope on either side of this line. It is also the case that IQ scores can vary greatly amongst tests when scores are low meaning that variation of scores is greatest at the end of the bell curve where diagnostic decisions are being made. Current guidance focuses more on adaptive behaviour as a measure of ID severity although the same “cut off” critique applies and the two assessments are poorly correlated with one another (Whitaker, 2013b).

Furthermore, doubt can arise not only from the measurement itself but the cause of the underlying impairment that the measurement represents. The concept of ID as an incurable condition underlies assessment and diagnosis. IQ scores however have been known to be affected by a vast range of modifying factors such as culture, ecological pressures, language and educational access (Ardila, 1995). It is of note that cognitive testing is largely understood to have been used to try and legitimise racist legislation against immigrants and people of colour, particularly African-Americans in the US in the early 20th century (Bruinius, 2006). Where neuropsychological testing has started to concern itself with validity in different cultures and ethnicities, known as cross-cultural neuropsychology (e.g. Fletcher-Janzen, Strickland, & Reynolds, 2013); intelligence testing and therefore ID diagnoses, which usually occur outside of specialist neuropsychology services, still rely on a single cognitive assessment, that is normed on a largely white, non-ID diagnosed population (Brue & Wilmshurst, 2016).

1.1.5 Redefining disability

The treatment of people considered different from the rest of a society's population is evident throughout history. The medical model of disability is critiqued for conceptualising this difference as residing within the individual rather than in the practices and construction of differences in society (Abberley, 1987).

1.1.5.1 The social model of disability: The social model instead understands these difficulties as a result of the barriers that society puts on disabled people due to a lack of appropriate adaptation for these impairments (Oliver, 1996). Further challenges came from the Union of Physically Impaired Against

Segregation (UPIAS, 1975) marking disability as a form of oppression, disabled people's experience is of society inflicting disadvantage upon them. Oliver's (1996) conceptualisation of disability echoes that of the historical context of people with ID who started to experience state sanctioned segregation due to changes in work patterns towards an industrialised, capitalist system that required individuals to work in ways structured against those who could not compete for labour. Pressure on WHO caused them to revise their definition of disability into a "biopsychosocial" model, to try and account for the contextual factors involved (WHO, 2001).

1.1.5.2 Criticism of the social model: The social model has also been critiqued, largely from post-modernist approaches that contest the structural nature of the model that continues to reify the existence of an "impairment" that requires a materialist solution and ignores how prejudice can manifest in culture (Rapley, 2004). Confusion also exists as to what is meant by the "social model" across nations; in the USA this takes on the form of a minority rights movement that focuses more on identity (Danforth, 2001) than social structures. Further criticism comes from the conceptualisation of oppression of people with disability as occurring only at the macro-structural level, whilst ignoring the lived and private experiences of people considered impaired (Owens, 2015).

1.1.5.3 A pragmatic response to "intellectual disability": Criticisms of both the social and medical model of disability have been made. The post-modern critique however also fails in its pursuit by refusing to stake a path for its position of preferred change, a model requires a path for action beyond critique. By highlighting the construction of disability under the broader construction of society itself can lead to a "launch [of] multisyllabic prose across abstract clouds, never to come to practical earth" (Danforth, 2001 p.355). Instead, a pragmatic approach is called for to create a cross "border" debate where limitations of all epistemological positionings on "disability" are recognised. Richer forms of knowledge can be held pluralistically *and* judged on their utility to ensure social justice for a marginalised group.

1.2 Towards a 'normalised' life

As the latter half the of 20th century saw care moving from the hospital to the community, the experiences of this group and the challenges they face would take a different turn.

1.2.1 The normalisation revelation

From the 1960's onwards, institutionalised care was losing public appeal. In the USA, John F. Kennedy appealed to a more receptive public calling for a restoration and revitalisation of concerns for the individual rights of marginalised people, including those with ID (Carnaby, 2018). In the UK, care was advocated for in the community rather than the hospital (Whitaker, 2013b). The *Better Services for the Mentally Handicapped* white paper (DH, 1971) called for the move from hospital to community care. Over the subsequent 20 years, the national debate culminated into the National Health Service and Community Care Act 1990 where deinstitutionalisation was brought into law. Where possible, people with ID were to be helped to live as "normal" a life as possible.

Normalisation has its origins with Niels Erick Bank-Mikkelsen following the Danish Mental Retardation Act 1959, which sought to ensure that the benefits of Danish social democracy could be available to all its citizens (Bank-Mikkelsen, 1969). Other Nordic countries followed with Sweden making changes to their services that focused on creating a *rhythm* of life, providing a normalised structure for people with ID that included typical life cycles and relationships within the economic/environmental context (Nirje, 1982).

Normalisation principles are often credited to the American psychologist Wolf Wolfensberger who laid out the foundations for people with ID and challenging behaviour to be supported in as "ordinary" way as possible in their housing, activities and living conditions (Jones, McWade, & Toogood, 2016).

Wolfensberger (1972) put forward two dimensions to normalisation; interaction and interpretation. He argued that the latter was crucial in order to understand how people with ID are devalued by the rest of society and its structures such as placements in undesirable areas or negative portrayal in the media. The aim was for people with ID to live their life within the same areas and using the same institutions (e.g. schools) as the typical population (Thomas, 2017a).

In the UK, normalisation processes began to be implemented through service-based achievements in what became known as “person-centred planning”. The main accomplishment was to ensure a community presence for people with ID in a variety of contexts, giving choice for people with ID to make their own decisions and the learning of skills that reduce dependency. Services had to lead in treating people with ID respectfully and fostering participation in new and existing relationships (Carnaby, 2018; O’Brien, 1987).

1.2.2 Critiques of normalisation

Normalisation, despite its radical vision for addressing inequality of experience for people with ID has been subject to criticism since its conception in the 1960s/70s. Perhaps the earliest criticism came in its application, where normalisation didn’t mean people with ID leading their own normal life, but to lead a life that is normal to the state or indeed making people with ID “normal” (Culham & Nind, 2003). This led to reports of normalisation “window-dressing”, whilst institutionalised practice continued within services (Thomas, 2017b). Wolfensberger addressed these issues where he felt many had misrepresented him. In 1992 he constructed *Social Role Valorization* as a theory that was more readily attributed to its core value of understanding the process of valorising the de-valued. He sought to move away from a model towards an overarching metatheory for undersetting the (empirical) nature of social relationships and human services (Wolfensberger, 2011).

Further criticism was made of the theory itself, Szivos claimed the normalisation had an inherent focus on differentness, where difference is seen to be something to remove and therefore denied. Normalisation was said to therefore portray ID as something that cannot be “valued in its own right” (1992 p. 126). Like the social model of disability, criticism has come from post-modernist thinking that challenges the notion of impairment residing within the individual (Yates, Dyson, & Hiles, 2008). In fact, criticism can be drawn from Festinger’s (1954) work on social comparison theory before normalisation’s ascent. He claims that people are more comfortable interacting with people similar to themselves, which suggests that a normalisation environment could in fact be detrimental for people with ID. Evidence on wellbeing in black and ethnic

minority (BAME) groups suggests that integration without addressing underlying inequalities may have a detrimental impact on marginalised groups. Rates of severe mental illness were found to be higher in people from a BaME background who lived in white majority areas compared to areas that were more ethnically diverse (Boydell et al., 2001; Das-Munshi et al., 2012).

1.2.3 Normalisation in Policy

Despite the criticisms of the normalisation approach, British policy continued to espouse this model to improve the lives and services of people with ID. The major pieces of legislation to come out of the department of health were *Valuing People* (DH, 2001) and its 8 year follow up, *Valuing People Now* (DH, 2009b). *Valuing People* aimed to tackle poorly coordinated and planned services for children and adults with ID and their families. It recognised that support was currently insufficient where people with ID experienced inequalities in housing, day services, employment and healthcare. People with ID were also acknowledged to have little control over their lives. The department of health therefore set out a normalisation agenda by focusing on the rights, independence, choice and inclusion of people with ID in society.

Despite *Valuing People*, people with ID were still being excluded from the services that others benefit from and continued to have little control over their own lives. The *Our Health, Our Care, Our Say* white paper (DH, 2006) stated the ongoing inequalities for people with ID, but it was the *Death by Indifference Report* (Mencap, 2007) that highlighted just how much people with ID's health needs were neglected. It criticised healthcare professionals' understanding and attitude toward people with ID and accusing the NHS of "institutional discrimination" (p. 1).

The Michael Report (2008) set out core standards for better health and making reasonable adjustments for people with ID in health settings. Tensions were described due to an inflexibility of the system where people with ID must "fit" to it. Waiting time expectations were found to be too high and communication breakdown meant vital information was not disseminated, health staff had little knowledge of the behaviour and cognitive needs of people with ID. In response to these concerns, the government set out a three year plan called *Valuing*

People Now (DH, 2009b), which sought to create greater personalisation for people with ID, ensuring that they can have a life where access to a full range of services is available, including for those with complex needs. The NHS was planned to be more flexible to the needs of people with ID, particularly generic primary and secondary care services where lack of understanding and negative risk attitudes has blocked entry to services.

1.2.4 Post-normalisation

Normalisation has seen the championing of supported living but has struggled to conceptualise how power imbalances are asserted within society and services. Gilbert (2003) suggests that power can be seen to circulate across community care services, with targets being the individuals with ID as well as their care workers, organisations and communities. Through normalisation and contracting, he claims that discourses have provided a hegemonic view of the “supported living” model, with little room to critique or challenge these dominant narratives. Where pluralistic democracy is taken out of the social care system, care providers can again “window dress” where local policies can appear to be driving equity, but culture and individual practice can see little change. Haydon-Laurel et al. (2017) found that despite the term “challenging behaviour” appearing in many service descriptions, people with ID were rarely spoken to about it. Coming across the term instead through names of services or over hearing care staff talk about it and them. People with ID spoke of a dislike for the term and preferred descriptions of their difficulties

Equally, care givers can struggle to apply the disability policy and the values embedded in them, particularly for people with the most complex needs. Those with more severe ID or in psychiatric crisis can experience increasing discrimination as a result, where staff are not prepared to support individuals with higher needs (Bigby, Clement, Mansell, & Beadle-Brown, 2009; Spassiani, Abou Chacra, & Lunskey, 2017).

Possibly the biggest challenge to the success of the *Valuing People/Now* agenda was when BBC Panorama uncovered a shocking level of abuse occurring at a privately operated assessment and treatment unit called Winterbourne View (BBC, 2011). The extent of failures in caring for such

vulnerable people resulted in a moment of reflection on the state of affairs for many people with ID up and down the country. What followed was a flood of more vigorous action and policy to ensure that people with ID, especially those under inpatient care, received the right support. Entitled *Transforming Care* (DH, 2012a) and followed by the Bubb Report (2014), the commissioning of services was to expand the number of community places for people with ID and reduce any inappropriate inpatient placements. *Building the right support*, a national plan to achieve this, was published following the Bubb Report (NHS England, 2015).

There are many aspects of a support worker's role where abuse of power can be exerted, this can be in the management of financial affairs, the neglecting of emotional and physical needs, overuse of restraint or restricting the person with ID's access to friends and loved ones. Much of these abuses would be considered a criminal act, such as using restraint in such a way as to commit assault. Medication, however, appears to lie within a different, more complex context. It continues to be a daily part of the life of many with ID; argued that when prescribed rationally and in accordance with guidance, can be of use in reducing distress for people with ID (Sheehan, 2018). Yet, despite this, running alongside the overt abuse of these exposés, was an overreliance on medication and poor medication practice (CQC, 2011).

The NHS released the *Winterbourne Medicines Programme* to improve prescription and administration to avoid medication being used as a "chemical cosh" (NHS IQ, 2015 p. 3). Public Health England released guidance for GPs in pre-screening psychotropic medication (PHE, 2015). The use of psychotropic medication in this group of people, usually prescribed as a means of controlling behaviour, will now be explored further below.

1.3 Use of psychotropic medication

The terrain of knowledge around the support worker context of using psychotropic medication in ID was reviewed. The databases of Scopus, Academic Search Complete, PsychInfo and PsychArticles were searched using the terms "intellectual or learning disability" and "medication" and "support

worker or care worker”. Using these terms produced eight results, of which one was relevant to this review.

Due to the sparsity of results from these search terms, it was decided that separate literature searches will be completed to determine two key areas of interest; the use of psychotropic medication in ID, and the experiences of support workers for people with ID. Search terms for the former were “intellectual disability or learning disability” and “psychotropic medication or psychiatric medication”. For the latter these were “intellectual disability or learning disability” and “support worker or care worker”

To ensure a concise and current summary of the literature, articles were prioritised that were less than 10 years old, except where there was significant citation to sources before this date. Studies were filtered based on their relevance to the area of interest, for example, studies using medications that were not psychotropic were excluded.

1.3.1 The medicating of people with intellectual disability

People with ID have been medicated with psychotropic drugs since compounds were discovered that had mood or behavioural altering effects. The first “antipsychotic” was made during the 1950s in France, when a pre-anaesthetic medication (chlorpromazine) was found to reduce experiences of hearing voices and unusual beliefs. Due to its highly sedative properties in suppressing the central nervous system, these drugs were originally known as “neuroleptics” (Bentall, 2010). Crippling levels of dosage however were given to induce Parkinson’s type symptoms as at the time, it was thought these side effects were directly linked with any reduction in psychotic symptoms (Levitas & Hurley, 2006b).

These drugs became an all-purpose approach to any major psychiatric disorder, people with ID who portrayed behaviour considered out of control were assumed to have schizophrenia and were therefore treated with antipsychotics. People with ID could not speak out and the drug’s lack of efficacy resulted in a major overuse and larger doses than in a neurotypical population (Levitas & Hurley, 2006a). In the US, a spate of legal actions e.g. *Rogers v. Commissioner*

of *Department of Mental Health* (1983) resulted in withdrawals, but when used indiscriminately caused tardive (involuntary movements) effects so severe that people with ID ended up on higher doses of antipsychotics to reduce the withdrawal effects. As new-line antipsychotics became available with less tardive movement issues, Risperidone became the drug of choice to replace older antipsychotics (Levitas & Hurley, 2006a).

1.3.2 Efficacy of medication

A range of studies from single cases to large RCTs (randomised control trials) have investigated the efficacy of psychotropic medication to treat people with ID, most controversial is their use to treat challenging behaviour, where no diagnosis of mental illness exists.

There is currently little evidence for the use of medication as a frontline treatment for challenging behaviour. Six systematic reviews over the past decade have found little evidence for the use of a host of psychotropic medications including anti-psychotics and medications of different classes. Efficacy is lacking regardless of the type of challenging behaviour, including aggression, with only Risperidone showing evidence for reducing aggression in individuals with ID and autism (Deb, 2007; Matson & Neal, 2009; Roy, Hoffman, Dudas, & Mendelowitz, 2013; Sawyer, Lake, Lunsby, Liu, & Desarkar, 2014). A major systematic review published in *The Lancet* found no difference between Haloperidol, Risperidone or placebo in the reduction of aggressive behaviours in people with ID (Tyrer et al., 2008).

The evidence of the use of anti-psychotics in people with ID even where a diagnosis of mental illness is made still fails to support its use when compared to people without ID. A Cochrane Review eliminated all studies found for the use of Clozapine in the ID population with a diagnosis of schizophrenia due to insufficient control groups. Most prescribing is based on evidence in the neurotypical population, lack of evidence in this case was considered an urgent issue (Ayub, Saeed, Munshi, & Naeem, 2015). Where smaller studies were reviewed, evidence was considered inconclusive at best (Singh et al., 2010).

Given the evidence, emphasis is on non-medical approaches to behaviour and a sparing use of psychotropic medication in strict adherence to national/international guidelines (Deb et al., 2009; Unwin & Deb, 2010). There is a growing concern over serious side-effects from psychotropic medication usage where the ID population has been found to be particularly susceptible compared to non-ID individuals (Sheehan, Horsfall, et al., 2017). Anti-psychotic medication comes with a range of side-effects, which includes weight gain, heart rhythm abnormalities and changes in blood sugar and lipid levels (Deb & Gomez, 2010), more serious and irreversible side-effects involve the central nervous system known as Tardive Dyskinesia (TD), a currently irreversible disorder of repetitive movements (Levitas & Hurley, 2006b).

Risk of side-effects are greatly increased when multiple classes of drug are used and in higher doses (Hess et al., 2010; Valdovinos, Caruso, Roberts, Kim, & Kennedy, 2005). Factors involving the individual were also found to affect side-effects; the more severely impaired and aggressive the individual, and the older they were, the greater the side-effects, especially TD (Matson, Fodstad, Rivet, & Rojahn, 2009; Matson & Neal, 2009). Worryingly, those most likely to be on medication due to challenging behaviour are those most likely to get side-effects.

Guidance now states that medication should be restricted only to occasions where a diagnosable mental illness has been identified or where challenging behaviour continues despite psychological interventions. Preference is stated for approaches that seek to understand challenging behaviour in the context of the wider environment and support systems that circle the individual (Murphy, 2017; NICE, 2015).

1.3.3 Current Practice

Over 30 years ago psychotropic medication amongst individuals with ID, who were going into the community, was noted to be on the decline with a rational approach to prescribing expected (Deb & Fraser, 1994). With current research and guidance making evidential claims against the wide use of psychotropic medication, the result would be expected that medication usage would reduce for this cohort. Audits of NHS trusts in the UK, however, have found that

psychotropic medication usage in services is high despite guidance (Paton, Bhatti, Purandare, Roy, & Barnes, 2016; Sheehan et al., 2015). Many people with ID are still being prescribed psychotropic medication for challenging behaviour and in some cases with no clear reason documented by the prescriber. Use of more than one psychotropic medication was also found to be common (Chapman, Gledhill, Jones, Burton, & Soni, 2006; Marshall, 2004; Sheehan et al., 2015).

In residential settings, the most widely used medication class for behaviour was antipsychotics (Robertson et al., 2008) where risperidone is regularly used off licence to manage aggression (Ghosh, Arulrajan, & Baldwin, 2010). Other issues also arose within community based samples, including the use of covert medication. Halder, Durairaj, Aslam, & Chaudhry (2012) found that in cases of covert administration, documentation of mental capacity was poor and that pharmacists were rarely involved despite bioavailability issues of changing the constitution of medication. A community NHS trust audit found 37% of their individuals with ID were on psychotropic medication to support their behaviour (Bowring, Totsika, Hastings, Toogood, & McMahon, 2017).

Where evidenced based prescribing could be effective for reducing aggression and improving quality of life, a lack of formulation before prescribing, more monitoring of side-effects and documentation (Deb & Gomez, 2010; Paton et al., 2016; Scheifes, Egberts, Stolker, Nijman, & Heerdink, 2016; A. N. Singh & Matson, 2009) continues to contradict guidelines.

1.3.4 The current alternative to medication

Where evidence for psychopharmacological approaches is limited, guidance has moved towards alternatives to managing challenging behaviour without medication.

One of the most popular and wide-spread approaches is known as Positive Behaviour Support (PBS). Developed on behavioural principles within a humanistic framework of relating to people with ID, it seeks to understand behaviour in the context of the individual's experience and their environment (*for summary see Gore et al., 2013*). Under normalisation policy, PBS has

become a catch all framework for proactive and respectful non-medical interventions based on skills teaching for problematic behaviours/environments and commitments to person centred values within ecological systems (Bambara, Dunlap, & Schwartz, 2004). Where the PBS approach is not adhered to, the result can be medication usage or other restrictive practice (Jones, 2017) and the risk of adverse effects (Deb & Fraser, 1994). PBS has not only gained support from within services, it is now the recommended approach by the Department of Health in order to support “positive and proactive care” (DH, 2014 p. 20).

Recent attempts to measure the effectiveness of PBS using randomised control trial (RCT) designs has shown some positive results. McGill et al., (2018) conducted one of the only RCTs for a non-medical intervention for challenging behaviour. They found a significant reduction in challenging behaviours in adults with ID compared to the control group by using setting-wide PBS, meaning its principles and intervention were used not only for the individual and immediate staff team but the broader environments and social influences that can impact on challenging behaviour.

1.3.5 Stopping the Over-Medication of People with Learning Disabilities, Autism or Both (STOMP)

As evidence for alternatives to medication have grown and the lack of efficacy and severity of side-effects is fully recognised, reductions have therefore become an area of need for ID services.

In July 2015, NHS England published a letter that set out the findings from a number of projects and audits of NHS services, as demonstrated in section 1.3.3 people with an ID/autism were being medicated at disproportionately high levels (Slowie & Ridge, 2015). After the creation of STOMP in 2016, further guidance was created for primary care practitioners, namely GPs and social care workers in order to enact this process (NHS England, 2017). Expectations from STOMP were that frameworks be followed or put in place to withdraw individuals from psychotropic medication that they need not be on.

The withdrawal of medication, however, is a relatively under researched area and with little clinical studies to guide practice, withdrawal for people who have been on antipsychotics is a complex and gradual process (Levitas & Hurley, 2006a).

Psychotropic withdrawal however is possible with medical management and a supportive social environment (Ahmed et al., 2000), and should enough attention be paid to the withdrawal process, side effects are limited (Jauernig & Hudson, 1995). More recently, Adams & Sawhney (2017) reported the successful discontinuation of carbamazepine and olanzapine from long term usage in a single case study, with additional benefits of reduced fatigue, improved emotional expression, and a decrease in weight. Similar results were found for the withdrawal of Risperidone where no increase in irritability was found (Ramerman et al., 2019). In a large cohort study, de Kuijper & Hoekstra (2018) found a 40% achievement in discontinuation and maintenance of long term psychotropic withdrawal. Some evidence also exists that withdrawal of sodium valproate may even reduce violent behaviour (Pritchard et al., 2014).

Although the STOMP campaign has kept the issue of overmedication alive, it is yet to effect real change and there remains much scope for improving the prescribing of psychotropic drugs for people with ID. Inappropriate maintenance of pharmacotherapy continues due to evidential or practical barriers in implementing alternatives. There is a need to further explore shared decision making and calls for qualitative research into attitudes of individuals with ID towards medication and of those in their system of support (Sheehan, Strydom, Morant, Pappa, & Hassiotis, 2017).

Lee, Rhodes, & Gerrard's (2019) case study relays the benefits of taking a PBS approach to reducing psychotropic medication usage for behaviours that challenge. Medication was found to be safely reduced and individual quality of life increased when PBS was used as an alternative. The researchers call for more research into how STOMP and PBS can work together for safe medication reduction and improved quality of life.

Even to this date, prescription of psychotropic medication remains high and STOMP is not visibly in place across NHS trusts and other services. In Robinson's (2019) commentary on the above study, he surveyed over 1000 people with ID in his service, over half were on psychotropic medication, with almost all prescribed one or more medications for at least six months. Despite the high prescribing, around a third had not had professionals review within the past year. Less than 15% has a specific plan in place to reduce or stop psychotropic medication.

Individual studies have found successful means to reduce medications safely and with improved outcomes for people with ID. Services as whole are slow to uptake or implement these ideals. Improving the use of psychotropic medication requires concerted action, adequate social support, and the provision of alternative, non-pharmacological interventions that are acceptable and effective. These are not available widely enough (Sheehan, 2018).

1.4 The role of care (support) workers

As people with ID began to transfer from long stay hospitals into community based residential services so there was a change in the staff paid to carry out this care. Where highly paid medical staff would oversee the day-to-day care of people with ID, in the community, this now fell to support workers, where little experience or qualifications were required for this role (Whitaker, 2013b). With many people with ID coming out of long stay institutions already on a number of psychotropic medications, responsibility for the administration of these medicines would also pass over to support workers and fall within the broader structures of ID care providers.

1.4.1 Care workers as an underprivileged workforce

Despite the benefits to quality of life and reduction in abuse since long stay hospitals closed, care workers have had high profile media coverage for different reasons. The *Winterbourne View Government Response* highlighted the dangers of isolated services, unskilled workers and an entrenched negative culture that impacts on the care provided for people with complex needs. Where many areas of failure came out of this report, the staffing context was significant

(DH, 2012b). A number of the support workers had no previous experience of working in care, let alone a hospital unit for people with complex support needs. These were significant findings in terms of risk to patients and staff from inexperienced care. Training and appropriate supervision for support staff was lacking with a poor understanding of accountability (CQC, 2011).

Support workers represent a group of staff that are underprivileged relative to other service staff (e.g. medics, psychologists). The social context of this role is important to understand when evaluating the service that is expected of them from those in more senior positions. The majority of the adult social care workforce are female and are employed on low wages. There is a high percentage of zero-hour contracts and staff turnover is high for this group. Due to the work pay and conditions, a low socio-economic status is resultant for many of this group. In urban areas care workers are represented by a large non-British cohort and black/minority ethnic (BME) groups, particularly in London (SfC, 2017).

Given the representation within the care workforce, it is clear how the hierarchies within this sector are both racialised and gendered, where exploitation is highest in domestic care where workers are predominantly women from non-British, ethnic minority backgrounds (Ally, 2005; Romero, 2012; Williams, 2010). Conflict between family and personal demands with work and job uncertainty limits opportunities for personal advancement (Hatton, Brown, Caine, & Emerson, 1995). Feree & Roth (1998) cite a lack of feminist and union movements representation within care work, suggesting a weakness in structural and organisational support for this employee group.

Oppressive conditions can impact on the way in which direct care staff treat the people they support. In nursing staff, disempowering work expectations were found to influence their own patient-orientated behaviour, coined “oppressed oppressors”, where equal conditions for nursing staff was deemed to be essential for equality of care provision (Rooddehghan, Parsa Yekta, & Nasrabadi, 2015). Where nurses experienced equity themselves, they provided patients with the experience of equity (Rooddehghan, ParsaYekta, & Nasrabadi, 2019).

1.4.2 Wellbeing and support for care workers

As an already underprivileged group support workers also face a number of challenges within their role. The majority of the literature exploring support workers in ID services focuses on “burnout”. Burnout is defined as a “syndrome of emotional exhaustion, depersonalisation and reduced personal accomplishment that can occur among individuals who do people work of some kind” (Maslach, Jackson, & Leiter, 1996 p.192), placing support workers at risk. Burnout theory suggests that *coping* will mediate the impact of work demands on wellbeing whilst *support* will moderate it. The importance is usually placed on the adoption of adaptive coping and how maladaptive coping can lead to emotional exhaustion (Devereux, Hastings, Noone, Firth, & Totsika, 2009).

Work stress for support workers in ID services has been described as an epidemic, with links to depression. Work overload, limited decision making, and external locus of control where all related to burnout (Gray-Stanley et al., 2010; Gray-Stanley & Muramatsu, 2011; Outar & Rose, 2017). Smyth, Healy, & Lydon (2015) found that burnout and emotional exhaustion was highest amongst those experiencing greatest challenging behaviour and affected their commitment to work. Fear of potential assault is considered a mediating factor between challenging behaviour and burnout (Mills & Rose, 2011).

In fact similar stressors were also found to impact on the intention of support workers to quit their job (Gray & Muramatsu, 2013) reinforcing the notion that burnout staff may not stick around, increasing transience in the workplace and its impact on those within it. Risk of emotional dis-attachment to people with ID is a consequence of burnout (Alexander & Hegarty, 2000). Blumenthal, Lavender, & Hewson (1998) found that organisation change can have an impact on the levels of stress and feeling of insecurity in support workers. The relationship between direct care staff and external professionals has an impact on team climate and wellbeing where collaboration with staff and involvement in decision making benefits this (Rose, Ahuja, & Jones, 2006).

Specific training can increase perceived confidence in working with challenging behaviour (McDonnell et al., 2008), where work based social support and stress

management resources can reduce burnout (Gray-Stanley & Muramatsu, 2011). Use of mindfulness for care workers can reduce the use of physical restraint of people with ID (Singh et al., 2009).

1.4.3 Care workers in the literature

Outside of staff wellbeing, care workers lack presence in the literature. Little has been studied in terms of support workers beliefs and experiences about different aspects of their role, with only a handful of studies exploring this. Being involved in restrictive practice can have a particular impact on support workers, Bethel & Beail (2013) found using mechanical restraints on people with ID had a negative impact on staff. They felt concerned about the impact of using them; coping with this consisted of reframing their own concerns and inhibiting emotions.

Supporting people with ID to make decisions is also a key role of the support worker. Support workers were found by Bigby, Whiteside, & Douglas, (2017) to have to juggle competing demands between their duty of care for the person they support verses the dignity of risk, where duty may clash with the person's right to autonomy (Perske, 1972). Formal systems have been criticised for being configured in ways that affect individual autonomy, Petner-Arrey & Copeland (2014) found that support workers were often frustrated with trying to help the autonomy of a person with ID. Constrictions of the service to reduce risk hindered support workers, the authors conclude that risk management is largely to protect the company from liability.

A small number of studies have explored support worker 's views on the medication they administer. Donley, Chan, & Webber (2012) found that support workers, desired more training around psychotropic medication, especially side effects and alternatives. The Nora Fry Centre (n.d.) at Bristol University produced a booklet called *medication matters* that reported on the medication knowledge of support workers. They found that support workers knew about names of drugs but less about dosages and were uncertain of potential side effects. Support workers were only as sure about medication longevity as far back as they had worked for the service.

Christian, Snycerski, Singh, & Poling (1999) found that support workers lack the knowledge and training in medication, which impacts negatively on the effective monitoring of pharmacotherapy. Despite gaps in knowledge, support workers were able to demonstrate their view on medication, its benefits, and alternatives such as more support hours or psychology referrals (Hall & Deb, 2008). These views however have not always been accepted by those holding more senior positions within ID services. Lalor & Poulson (2013) constructed themes of powerlessness and marginalisation of care staff from their interviews with them. Support workers were seen as resigned to their status; they recognised their skills in understanding the people they support and their role in advocacy, but this was rarely utilised. Lack of training in psychotropic medication was seen as impacting on both them and the people they care for.

Support workers have the potential to play a significant role in the psychotropic medication management of the people they support. Interviews with people with ID found that they lacked knowledge about their medication other than the routine around it. They reported that side-effects were told to support workers but these were not understood to be listened to and so not passed on to medical professionals (Crossley & Withers, 2009). The knowledge and engagement with medication therefore has a direct impact on the people they support; Donley et al. (2012) suggests that the support worker role in psychotropic medication can greatly influence the decision making of GPs and psychiatrists, as their prescriptions are largely based on the information given to them by support staff.

Iacono (2010) warns that if the needs of support workers continue to be neglected. This carries the risk that people with ID will be reliant on well-meaning but poorly supported staff at best, and unengaged, poorly trained support workers at worst. Petner-Arrey & Copeland (2014) makes a more damning critique of the intrinsic nature of the role:

“The support relationship is extremely problematic. This relationship involves paying one person to support another, and there is literally no way to pay someone to care” (p.43)

Simplican (2018) agrees that support practices tend to exclude people with ID but that care practice can facilitate better quality of life for people with ID when it is democratised. She calls for a better routine of supervision and feedback to measure performance, and to guard against workplaces cultures that undermine democratic principles of dignity, equity, and inclusion.

1.5 Current position of service for people with intellectual disabilities

Despite the outward projection from government and major service provisions to reduce inpatient stays, lack of appropriate resources to support community provisions mean people with ID continue to be subject to restrictive practice that does not meet their needs (Jones, 2017). *Transforming Care* (see Branford, Gerrard, Saleem, Shaw, & Webster, 2019b) has refocused the government's attention on ensuring that people can live closer to home, within their own communities and reduce the number of admissions to hospital. To achieve this, 48 transforming care partnerships were set up to oversee the local provision of services in adhering to these ideals. There is a particular focus on inpatient statistics where a monthly public report is released as part of *Assuring Transformation*. As of March 2019, there has been a gradual but consistent downward trend over the past 4 years of people with ID receiving inpatient care (NHS Digital, 2019).

Further monitoring and scrutiny however must continue to be placed on existing and new community provisions, the recent tragic failures that saw further abuses of people with ID (Somerset Safeguarding Adults Board, 2018) at Mendip house shows how inadequate management and oversight of services can lead to systematic abuse of people with ID by the support workers who are paid to care for them (Flynn, 2018).

1.6 Research aim and questions

Support workers play a crucial role in supporting people with ID, yet their experience of this position is largely under researched. Given the major reports of abuse in the past ten years, where support workers have played the direct

role in carrying out this abuse, there is a need to understand their context. This research will prioritise their view and experiences.

Support workers are involved in the delivery of a broad range of interventions for the people they support. Where abuse has happened, there has often been an associated over-reliance on medication to control behaviour (NHS IQ, 2015). Despite government legislating to reduce the overmedication of people with ID, audits have found that this still occurs, exploration is therefore needed as to how psychotropic medication is experienced within services.

1.6.1 Research aim

To gain greater insights into the practice of psychotropic medication in ID services and seek the participation of support workers, as a particular group of interest, in order to understand the medicating of people with ID from their perspective.

1.6.2 Research Questions

The following research questions will be addressed to understand the experiences of support workers for people with ID who take psychotropic medication:

1. What factors influence the support that support workers give to people with ID who take psychotropic medication?
2. How do support workers understand their role in medicating people with ID?
3. How does psychotropic medication impact on support worker relationships?

2. METHOD

2.1. Overview

The epistemological position of pragmatism will be explored and how this has both influenced the methodology of grounded theory (GT) and their

compatibility. Grounded theory will be briefly explained, leading onto the design and procedure of the study including the use of participants, any ethical considerations and how data was collected.

2.2 Pragmatism as a research paradigm

This study was undertaken from a pragmatist theoretical stance, which aims to assess the value of ideas on practical terms, it moves away from what can be obtuse and high-minded metaphysical questions about the existence of knowledge (Jones-Chesters, 2007). In this study, priority was given to generating new ways of conceptualising support workers' experiences and the process of supporting someone with ID who takes psychotropic medication. These conceptualisations emerged from the data gained from participants' insights into the research questions stated in the previous chapter.

Morgan (2014) describes the positions of relativism and realism, the world of our perceptions versus the nature of the outside world, as "discussions about two sides of the same coin" (p. 4). From a pragmatist position, the question around "knowing what reality is?" is short-sighted as "to know it [reality] means to neglect its flux and alteration" (Dewey, 1920 p.108); instead the question must be "how does this knowledge serve our purposes?". Pragmatism as a paradigm is credited to the North American philosophers of the late 19th Century. The three major contributors to the approach (CS Pierce, William James, and John Dewey) varied in how they saw pragmatism (Jones-Chesters, 2007) with James taking a more subjective view of the efficacy of "what works" than Pierce's impersonal, objective position. Regardless of these differences, modern pragmatism unlike realism does not seek to claim that knowledge reflects an underlying reality but instead that beliefs about the world depend on the consequences of acting on those beliefs (Cornish & Gillespie, 2009). Whilst being anti-realist, modern pragmatism is also considered non-relativist (Jones-Chesters, 2007); whilst it does resonate with the postmodern rejection of meta-narratives and ideologies it resists the ideas that "anything goes" (Ormerod, 2006) as pragmatism expects knowledge to be evaluated in terms of how it serves specific interests (Cornish & Gillespie, 2009).

2.2.1 Pragmatism on terminology

Within this study the diagnosis of ID will be used to describe individuals who have been given this diagnosis according to national guidance and diagnostic criteria (BPS, 2000; WHO, 2018). As outlined in chapter one, this diagnosis remains problematic both in terms of its social and historical context, as well as concerns of validity and reliability in current assessment measures.

This position rejects a realist interpretation of ID where current measures based on normal distribution of IQ is a mirror, as best as possible, of an underlying reality that is ID. Simply holding in mind the term “intellectual disability” does not represent a reality, in fact a truly “accurate representation... needs to be abandoned” (Rorty, 1979 p.6). Equally, this position does not align with a relativist account of ID, which would hold all accounts of ID as equally valid. Andrews et al. (2019) and Jenks (2019) warn of the adverse effects of the erasure of the word “disability” and the assumption of a unified disabled identity, such as being in the context of socio-political reality of budget cuts, austerity, reducing services, and doesn’t recognise impairment as a need to claim.

Whilst remaining pluralistic about what ID *is*, the theories and knowledge of what is called “intellectual disability” can be a tool for taking action through this understanding and can lead to support in improving the lives of people with this diagnosis. This thesis will therefore use the term intellectual disability throughout, not as a fixed truth but a fallible belief that can be revised.

2.3 Constructivist grounded theory

Grounded theory has been selected for this study due to its sensitivity to conceptualising psycho-social processes, constructing new models and bringing novel insights into areas where extant theoretical utility is lacking. The research aims and specific questions seek to construct a model to understand the role of support workers in the psychotropic medicating of people with ID, an under researched and concerning area of interest as laid out in chapter one.

Grounded theory is therefore an appropriate method for carrying out this research.

2.3.1 The emergence of grounded theory

Grounded theory has developed into multiple forms, with different proponents and criticisms. To understand the “type” of GT chosen for this research, it is important to summarise its history as a method. It first emerged from the tensions within sociology departments in the United States over preference for qualitative or quantitative research in the 1960s (Charmaz, 2014). Due to a perceived lack of analytic strategies in qualitative research at the time, two researchers at the University of Chicago, Barney Glaser and Anselm Strauss developed GT in their 1967 book *Discovery*. They aimed to bridge the gap between theory and research, “discovering” theory rather than deducing hypotheses from “grand theory” (Glaser & Strauss, 2000).

Over time the approach developed by Glaser and Strauss diverged marking the beginning of different strands of GT (see Bryant, 2017). Whilst Glaser continued with a highly objectivist GT methodology, Strauss and his co-collaborator, researcher Juliet Corbin, began to endorse a more reflexive role within the research whilst employing GT as verificational (Charmaz, 2014; Timonen, Foley, & Conlon, 2018).

In the 1990s, researchers in GT began to move away from the positivism of Glaser & post-positivism of Strauss & Corbin’s strands. Critics argued that the method was:

“clinging to an outdated modernist epistemology... fragmented the respondent’s story, relied on the authoritative voice of the researcher, blurred difference, and uncritically accepted” (Charmaz, 2014 p. 13).

Instead an approach was developed that views the research as constructed not only from the participants but the researcher themselves. From this perspective, theory is not discovered but generated, acknowledging the interconnectivity of researcher, participant, and the interpretations made (Tweed & Charmaz, 2012).

Charmaz's (2000) chapter put forward her development of *constructivist* GT that argues for less rigidity of GT strategies, focusing on meaning to further

interpretive understanding. She advocates for adopting GT strategies without a positivist approach in so far that causality is suggestive, incomplete and indeterminate. Given the positioning of this research on the understanding of terms such as “intellectual disability” as constructed, this form of GT fits the epistemological assumptions of the pragmatist approach.

2.3.1.1 Symbolic Interactionism: Symbolic interactionism describes how past experiences precede the individual in constructing society, where actions and interpretation occurs (Charmaz, 2014). It focuses on actors’ constant creation and recreation of experiences between the self and society, being fluid, and in constant flux (Carter & Fuller, 2015). Individuals are increasingly understood to be both products and producers of their social worlds (Uprichard, 2010) where constructivist GT provides a pragmatic method to explore this process. Symbolic interactionism and GT links the work of Henry Blumer with Glaser and Strauss, both part of the Chicago School (Blumer, 2009).

2.3.2 Key components of constructivist grounded theory

Despite the epistemological differences between classical GT and newer developments, the same core strategies from Glaser and Strauss’ original approach are transportable across these strands and maintain the approach as GT (Charmaz, 2014). Charmaz (2014) poses the following nine actions in order to evidence GT, with particular attention to action 1-5; namely going back and forward between inductive data and the analysis in an iterative process in order to construct abstract categories. Further components of GT are explained later in this chapter.

- 1 Conduct data collection and analysis simultaneously in an iterative process
- 2 Analyse actions and process rather than themes and structures
- 3 Use comparative methods
- 4 Draw on data (e.g. narrative and descriptions) in service of developing new conceptual categories
- 5 Develop inductive abstract analytic categories through the systematic data analysis
- 6 Emphasize theory construction rather than description or application of current theories

- 7 Engage in theoretical sampling
 - 8 Search for variation in the studied categories or process
 - 9 Pursue developing a category rather than covering a specific empirical topic
- (p.11)

2.4 A pragmatic approach to constructivist grounded theory

The assumptions around action and interaction that are key to the iterative process in GT stems from pragmatism, particularly of the strands from Strauss and Corbin onwards. Constructivist GT moves away from the position of making knowledge claims about an objective reality, however, stops short of the paradox of post-modernism, where a relativist view allows all claims to knowledge to be equally valid. This however *is* a knowledge claim meaning such post-modernist assumptions violate themselves. By refusing to recognise a preference of action, GT is incompatible with relativism given its interest in conceptualising processes to determine a preference of action (Charmaz, 2014).

Pragmatism avoids this paradox by recognising the fallibility of any belief as concrete, whilst also being anti-sceptic, ‘doubt’ demands justification (Jones-Chesters, 2007) as well as the basis of useful action. In this light, GT can be better understood. Grounded theory is criticised for using terms such as “fit”, “grab” and “usefulness” when analysing data; instead of being evidence of a conceptual weakness, the terms make sense when underpinned by pragmatist theory of *usefulness over truthfulness* (Bryant, 2017), where theories can be seen as “instruments, not answers to enigmas” (James, 2000, p. 29).

Pragmatism is described by (Charmaz, 2017) as the interpretive theoretical foundation with which constructivist GT is aligned. The historical context of pragmatism in social justice, life as social, and stability as problematic, complements the constructivist GT approach that meaning, and action influence each other and that individuals cannot be separated from their social realities.

Both the theoretical orientation of this research and the chosen method for the study are appropriate to the research aims. Constructivist GT is useful where

theory is lacking and specifies the implications of change in social situations where the phenomena occur (Tweed & Charmaz, 2012). Support workers often hold little power within larger health and social care systems whilst simultaneously working most closely with vulnerable adults and are regularly excluded from the research process. The expectation is that theory development will not represent an “answer” but can nevertheless lead to effective interventions to support the care workers and people with ID who take psychotropic medication. The position of pragmatism allows this question to be explored through the lens of utility and action, which is relevant to council and NHS structures. Unlike social constructionist models, this conditional view of truth opens possibilities of shift and change (Charmaz, 2017) where doubt must be justified as much as belief. This ensures that entrenched debates around high-theory do not lead to what has been coined “epistemology wars” (Jones-Chesters, 2007, p.253) at the expense of useful knowledge for social change.

2.5 Ethical considerations

2.5.1 Participants and the people they support

People with intellectual disability are some of the most vulnerable and socially excluded people in society (DH, 2001). A great deal of research focuses on behaviour perceived as challenging and what interventions can be put in place to reduce this, including medication (Deb, 2007). Whilst more research is focusing on improving the quality of life of people with ID, post-institution community living arrangements have been reported as less good than they should be given the current knowledge base (Clement & Bigby, 2010), where institutional-type practice still continues. Mansell and Beadle-Brown (2004) demonstrate the “implementation gap” between what is known to be beneficial for people with ID and putting it into practice. By focusing on the process of supporting people with ID on psychotropic medication, this study hopes to add to the literature the benefit of de-medicalising people with ID. The STOMP agenda has reached the national strategy level where a similar implementation gap appears to be present, it is felt that developing an understanding to bridge this gap is necessary.

The participants in this study also need ethical consideration. Support workers occupy a unique position within the literature in so far as they cannot participate in service user led research whilst also being at the bottom of the health and social care staff hierarchy. Despite their lack of involvement in research, much of the professional guidance from community ID teams (CIDT) could not be carried out without support workers to implement them. In order to address implementation gaps Mansell & Beadle-Brown (2004) recommended that the power relation between people who speak for those with ID and public agencies is addressed through strengthening their voice. They acknowledged that real change can only be made through direct and immediate work with front-line staff. This rich knowledge base that care workers hold about the people they work with needs to be understood and their voices heard within a system that often underrecognizes them. For this reason, it is considered justified to study care workers' experience.

2.5.2 Ethics procedure

Ethical approval was obtained from the University of East London Ethics Committee (see Appendix 1). The research has been created and the carried out in according with the British Psychological Society's Codes of Human Research Ethics (BPS, 2014)

An information sheet outlining the nature of the research was given to potential participants and contact details should they wish to ask any questions or concerns about the study (see Appendix 3). In order for participants to take part in the research, their informed consent (see Appendix 4) was given prior to interviews taking place. Participants had the right to withdraw at any time during the interview process as well as the right to refuse to answer questions asked of them without giving a reason. Following the interview, participants were verbally debriefed, having the opportunity to ask any questions that may have arisen from interview or about the future direction of the study

Information about the participants was anonymised with pseudonyms. Where participants were clearly identifiable (e.g. audio recording of interview, this had been stored securely and deleted once recordings have been transcribed). Only the researcher had access to audio recordings, whilst the supervisor had

access to anonymised transcripts. The participants had the right to have their data removed from the analysis, so long as this had not yet taken place, no participants requested for their data to be removed.

The research was supervised by a qualified clinical psychologist working within adult ID community services who acted as an external director of studies. Supervision was also provided by an internal member of the academic team at the University of East London.

2.6 Design

The aim of this study is to construct a model of psychotropic medication withdrawal as experienced by support workers for people with ID. From both a pragmatism position and when carrying out constructivist GT, the use of qualitative, quantitative and mixed methods data collection can be utilised. It is also possible to gather data from a variety of means or sources such as texts and documents, interviews, focus groups or observations. The logistical and procedural difficulties in acquiring broad data means that this thesis will focus on a specific type of data collection. Qualitative data was gathered using semi-structured interviews to gather the views of participants; whilst there was a brief interview schedule, precedence was given to ensuring that participants could tell their own story where the interviewer is reducing their influence over the data through an inflexible schedule. Due to these reasons, interviews are seen as a preferable method of gathering data for this study (Oppenheim, 2004).

2.7 Procedure

2.7.1 Initial groundwork

Managers and directors of ID services within the local council or third sector organisations were approached to determine if they were interested in supporting the research as an organisation and could advertise to their support workers. Due to the initial interest specifically in medication reduction (see section 4.4.2), it was identified with these services if they were currently or had historically supported their service users to reduce their psychotropic medication.

Once key stake holders within the organisations were satisfied for the research to be carried out within their service, a key manager was allocated to act as a line of communication between the service and the researcher. Support workers interested in participating liaised with the key manager as well as the researcher to organise a suitable time for them to take part, typically because this involved coming off shift.

Participants were not offered a direct financial incentive for taking part, it was however negotiated with the services that their support workers would be able to be interviewed during their working hours rather than their free time and so effectively being paid up to an hour of their usual salary, which was covered by their employer.

2.7.2 Sampling

The study has purposefully sampled individual support workers to interview who fit with the research questions i.e. caring/cared for people for people with ID who are having/had their psychotropic medication reduced (NHS England, 2017).

Data was collected in a specific way relevant to GT methodology, a method of constantly comparing between elements of the analysis allows for further coding and categorisation that is more focused and abstract. As tentative analytic categories were developed through codes, further sampling (see Appendix 6) occurred in order to answer questions that have come out of the previous analysis (Tweed & Charmaz, 2012). Grounded theory calls this theoretical sampling with the aim to seek pertinent data in order to elaborate on and refine an emerging theory (Charmaz, 2014)

This study sought a minimum of nine participants, although the process is considered to be non-linear and finishes when categories are either saturated or considerable data had been collected (Charmaz, 2014). Due to the time constraints on this study, saturation was not a reasonable criterion for ending data collection.

2.7.3 Inclusion criteria

This research involved individuals employed as support workers, all participants were over the age of 18, with no upper limit. For this research, participants must be employed as a support worker and working with adults with ID within a formal service designed and set up to care for people with this diagnosis. There was no expectation that support workers had occupied that role for any particular length of time, it was however necessary that participants not only worked with someone with ID but had experience either currently or historically of supporting someone with ID who was having their psychotropic medication reduced.

2.7.4 Participant demographics

Table 1: Demographic and additional information about participants

Participant	Job Title	Gender	Age	Ethnicity	Experience ²
P1	Sen support worker	Female	40-49	White British	20-29 years
P2	Support worker	Female	40-49	White European	20-29 years
P3	Support worker	Male	30-39	White British	10-19 years
P4	Support worker	Male	30-39	White British	0-9 years
P5	Support worker	Male	50-59	White Irish	10-19 years
P6	Support worker	Female	50-59	Mixed South American	10-19 years
P7	Team leader	Female	30-39	Black African	0-9 years
P8	Support worker	Female	60-69	White British	10-19 years
P9	Ass. Manager	Male	50-59	Black African	10-19 years³

All support workers who participated were currently employed by a service that provides social care for people with ID. Providers were either specialist outreach support, day service or supporting living settings. All participants had previously worked in a support role in at least one other service where people

² Number of years working with people with intellectual disability

³ Audio file corrupted, unable to transcribe

with ID were taking psychotropic medication, including educational services, residential care and inpatient settings.

2.7.5 Interviewing

The participants were orientated to the interview procedure including the checking of consent forms and had an opportunity to ask any questions about the study before the interview started. The recording of the interview was explained again. Interviews were conducted at the support worker's place of work. Interview rooms were selected for being quiet, unlikely to be interrupted and overheard. The interviews ran for between 45 to 60 minutes, they were terminated when a natural endpoint of the conversation occurred around this time.

Participants were asked some introductory questions around their entry into support work for people with ID in order to orientate them towards telling their story. The interview schedule (see appendix 5) was least structured for the first two interviews to reduce any preconceptions about the content of the interview direction (Charmaz, 2014). Questions were asked from the interview schedule in earlier interviews but not in any particular order. As theory development occurred by moving between the data and the analysis, the interview process was more structured to ascertain emerging patterns or categories for theory construction.

Throughout the interviews, questions looked to understand the broad areas of factors involved in the administration and reduction of psychotropic medication, their role in supporting people with ID during this reduction and the impact on their relationship to the people they support.

2.7.6 Data analysis

Transcription of the original audio data used an adaption of Parker's (2005) guidance on interview transcription to understand who is speaking, interruption and overlap, pauses, inaudible speech, and other important information to make sense of the text (see Appendix 14).

Data was coded and analysed using the guidance from Tweed & Charmaz (2012) and Charmaz (2014), which aims to make codes active, short, specific and spontaneous. By doing so, coding helped to engage the researcher with the data without applying preconceptions whilst enabling a process to define what was happening in the data, comparison and categorisation of data, and making connections between coding and data.

Grounded theory is concerned with process and thus initial coding was carried out using gerund words (e.g. defining, explaining). In addition to this, GT coding uses a line by line coding system to bring the researcher into each fragment of the data and make provisional codes to highlight gaps in the data and reoccurring concepts (Tweed & Charmaz, 2012). Coding then became more concentrated where *focused codes* are constructed from the most frequent and compelling codes, in order to analyse larger volumes of data for patterns, comparisons and gaps. Tentative, more abstract categories were then constructed in order to raise the codes to a more analytic level and to place them in their social context. Categories were compared back to the data, codes and other categories as an emergent process. As these ideas were worked with, greater theoretical sensitivity was achieved (Charmaz, 2014).

Building on the theoretical and more abstract categories, situational analysis was used. This is a process of mapping out in space, categories or codes to open up the data and interrogate it further. Schematics constructed can result in a conceptual model, but this is not the “aim” of the analysis. Situational analysis can conceptualise data in three ways; 1) situational maps: laying out the human and other situations of concern and how they relate 2) social world maps: laying out the collective actors in the arena they occupy and the negotiations between them 3) positional maps: laying out major positions, raising controversy or complications in the situation (Clarke, 2003).

2.8 Ensuring rigour

From the initial groundwork through to category formation and theory construction, memos were routinely taken. These can be seen as analytic notes in order to support the construction of theoretical categories, improve

productivity and a space to reflect on what the researcher is bringing to the analysis. Critical reflexivity is a crucial part of constructivist GT, which is supported through memo writing (Charmaz, 2014). The use of comprehensive literature reviews in GT are delayed until after data analysis has occurred. This is to ensure that the researcher reduces bias from extant theory or models and constructs theory directly from the data (Tweed & Charmaz, 2012). It is however understood that it is not possible to be truly naïve to previously researched area or familiar client groups. Every attempt has been made however, to remain curious about any themes that arise from the data, it is also the case that there are not any theories currently known to explain the processes explored within the specific context of this study.

This study further ensured rigour of the method through applying the guidelines set out by Yardley (2000). She proposes that the quality of a qualitative study can be assessed through attention to; sensitivity to context, commitment and rigour, transparency and coherence, impact and importance, and researcher reflexivity. These criteria are broadly represented in Charmaz's (2014) guidance around evaluating constructivist GT studies. These areas will be outlined further and used to critique and evaluate this research piece in the discussion.

3. ANALYSIS

3.1 Overview

The GT analysis will be laid out in this chapter as per the method above. The model constructed from this analysis represents how support workers negotiate their role with major actors in the social world of ID services and how this relates to their experiences with psychotropic medication. Attention is paid to these different roles and how positions of “ablement” and “disablement” are taken vis-à-vis these relationships. These positions are representative of a broader axis of “dis/ability” that runs through ID services.

The whole model will be outlined followed by an analysis of the core components of this model in more detail.

3.2 A constructed grounded theory model: negotiating the psychotropic medication role of support workers for people with intellectual disability

The “Negotiating Dis/ability Model” in Figure 2 was constructed through the iterative approach of GT, using constant comparisons of initial ‘line-by-line’ codes, focused codes, category forming and situational analysis. The model represents a conceptualisation that is believed to best fit the participants’ experiences and views put forward during interviews. This model can be seen as bringing into focus the core individual role of support workers, given their experiences as the focus of this study. Surrounding the support workers are the actors that are experienced to be the most relevant to support workers in supporting individuals with ID who take psychotropic medication. Support workers must negotiate these relationships with others in their service. “Negotiate” is used to describe the fluid navigation of difficult (medication) experiences with actors in the system. These were conceptualised as being between the support worker and the care provider managers, psychiatrist and people with ID themselves.

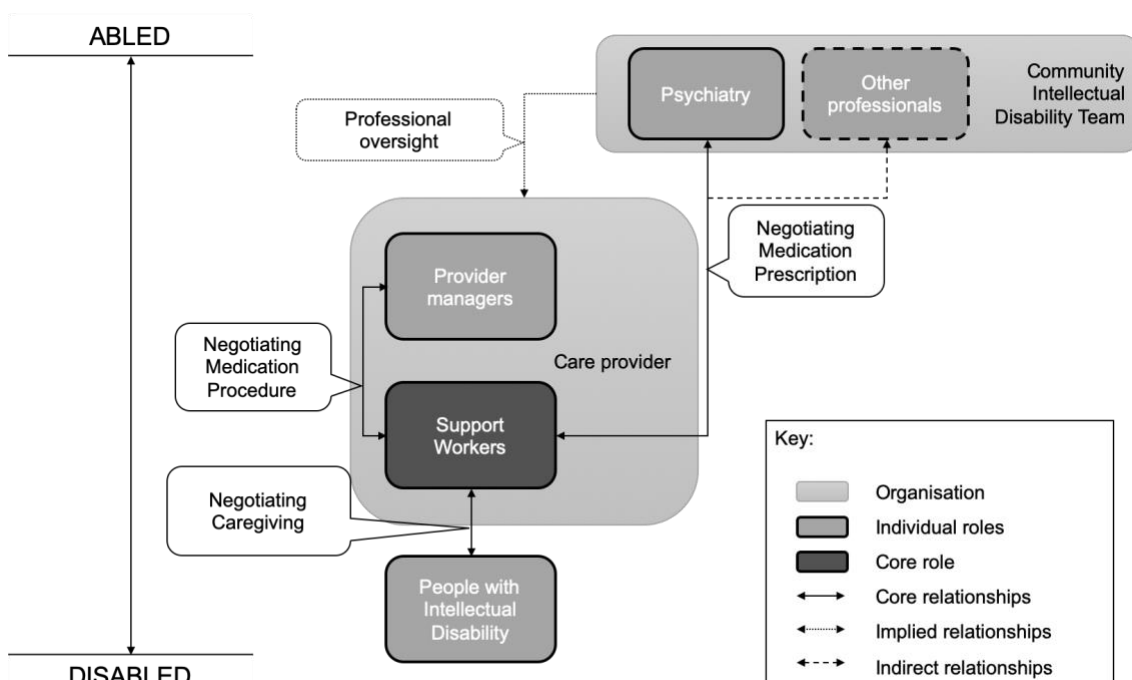


Figure 2: “The Negotiating Dis/ability Model”

Outside of the core processes, there is an implication that the community ID team overviews any clinical accountability for individuals supported by the care

provider. An indirect process was also identified between the support workers and other professionals in the (CIDT) such as clinical psychologists, who may be providing non-medical approaches to challenging behaviour (and mental health). This relationship could impact on the negotiating of medication prescribing between support workers and psychiatry, this has been portrayed as a mediating, albeit indirect process.

The individual roles and organisations have been conceptualised in their placing within the social arena/system. The construction of power within this relationship often related to the professional authority over another, the medication expertise and the physical/experiential distance from the direct impact of medication. These three concepts have coalesced around a continuum of “disability”, where individuals with an ID are regarded by services as being the most “disabled”, evidenced by the choice of “disability” in their diagnosis and as the recipients of statutory care services in the model. At the opposite end of the spectrum, the greater the constructed level of “abled”. This is represented at its most significant in healthcare professionals of the CIDT; Psychiatry for example, where medical qualifications, oversight, decision making, and the ability to prescribe medication are signifiers of “ability” in the system.

Support workers sit at neither extreme of this model, instead they are regarded as being more “able” than those with an ID but less “able” than provider managers and healthcare professionals. This hierarchy of ability means that a support worker sits in a unique position when considering their role in psychotropic medication; they hold the responsibility of administering medication whilst occupying a position of disability when it comes to the procedural and prescription decision making around medication. Within these relationships, support workers experience both “ability” and “disability” in negotiating their role around psychotropic medication. “Dis/ablement” can work itself up and down the axis of hierarchy within the system, where disabling experiences for support workers from those more “abled” can be reflected in their relationships with those who are “disabled”.

The model will now be explained in more detail by focusing on the relationship that the support worker has with each individual group in the model.

3.3 Negotiating the medication prescription role with psychiatry

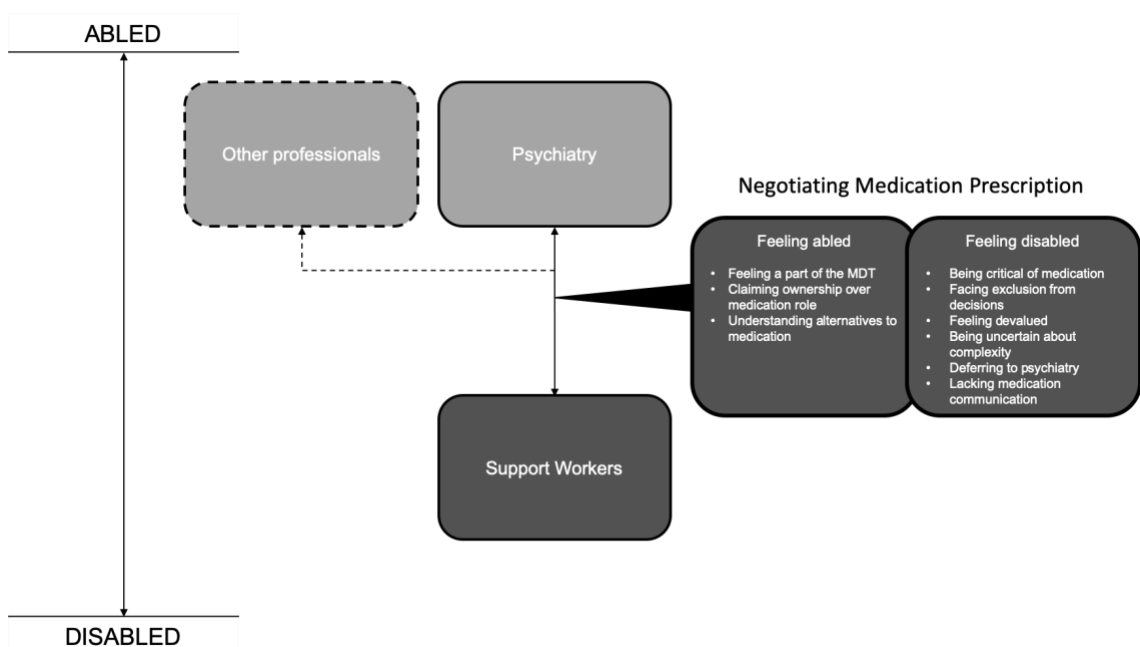


Figure 3: Negotiating medication prescription with psychiatry

The “negotiating medication prescription” relationships conveys how the role of prescribing medication is negotiated between the support worker and psychiatry (see Figure 3). Psychiatry, as the most medically “able” within the model, has control over the medical assessment of challenging behaviour and mental health problems, and its subsequent treatment with psychotropic medication. Support workers negotiate the difficulties around how psychotropic medication is prescribed in their relationship with psychiatry; these interactions are fluid, being experienced in different ways and at different times. The interpersonal process between psychiatry and support workers positions them in a “disabling” and/or “abling” role, where actions and beliefs maintain experience through their interaction with one another. Through conceptualising these experiences relating to “ability”, the relationship can be better understood in the context of psychiatry’s authority in imposing medical solutions onto support workers where they do not occupy a position of power within this negotiation. The relationship with other professionals in the CIDT is marked through its indirect involvement in psychotropic medication. Whilst important, they do not enforce either

prescription or medication procedures, so they are not represented as a key actor in this model but a mediating one.

The non-mutually exclusive positions of “disability” and “ability” will be constructed below, using excerpts from the interview data to support this conceptualisation.

3.3.1 Feeling “disabled” in prescription role

The following categories represent disabling relational processes with psychiatry as experienced by support workers. The positioning of both actors is most stark within this relationship given the distance between them in terms of “disablement” marking a particularly present power dynamic which was voiced by the participants.

3.3.1.1 Being critical of medication: Support workers experienced psychotropic medication as problematic in a number of ways, particularly for its use in challenging behaviour and questioning its use as a single intervention for these difficulties.

P1 describes her discomfort at the use of psychotropic medication where people with ID can no longer articulate themselves. She articulates her hopelessness in attempts to interact with the person she supports.

*“...what was kind of happening for you at that time when you noticed that shift between someone who was in this- in your words drugged up? (DW)
“...me going "you're going here you're doing this, we're doing that" and the person, not, not responding so much I find that quite- I don't like that, people don't tell me, when people don't- if somebody could say yes or no and they don't, I think I'm- that makes me feel a bit uncomfortable, and that's my own thing cause I was like well, hope you're not doing it to please me cause you know I'm not always right [laughter] that sort of thing, that's that vulnerability” (P1).*

P6 describes her experience of psychotropic medication replacing emotional support, where it is given quickly in response to a problem.

“the medication sometimes given too soon I think well you- you named about the emotional issues I think is very important. Especially people who have learning disabilities but say they on the- on the edge, not too bad, but of course emotionally they feel left out isn't it... but I think with the right support many people could, and many people have been able to, kind of over- overcome that and go a little bit further isn't it, and be more stable without needing medication” (P6).

3.3.1.2 Facing exclusion from decisions: Supports workers experienced being left out of the decision-making process about medication. Support workers reported this exclusion as a considered position from those with more authority to determine who attends medication reviews, granted through psychiatry's hegemonic prescribing powers.

P3 described what he could have offered to the decision-making process had it not been, for what he believed, was a vested interest in his exclusion from choices around medication.

“...there was information that you had that would have been relevant for them to know, that they maybe didn't or didn't think about?” (DW)

“Erm, I think - I think so, I think when maybe we could have talked about the er type of support that he you know was getting erm at the respite we maybe we would have given a more honest opinion... they are likely to keep- to keep that quiet because it's- it's- it would be you know a mark on them (P3)”

P6 describes how, despite being present in review meetings around medication, changes are made without her input or opinion being sought.

“As we talk earlier on, support workers are very undermined, you will find, we are not consulted [laugh], we are not asked [laugh], so that is how I've been, so er I have been some review meetings with some of my key work- key client, but I never have been kind of asked, consulted

about if it is okay to reduce, to put that person on medication to, never have (P6)”

P2 describes her experiences of long waits to see any healthcare professionals following issues around medication concerns.

“we tried to get er referrals through to, to review those things and there was an extremely long waiting list at the time, there was like this man will never had time to come and review these things.” (P2)

Of the support workers interviewed, out-reach staff had closer links to psychiatry than others due to the positioning of the organisation they worked for. These support workers spoke of disparity in access for other support workers they had contact with or in previous roles, this also represents a hierarchy of ability that exists not just between roles, but within them.

P1 compares her current role with experiences of those with less connection to the CIDT.

“I know from when I've been in other agencies and still working with people in supported living, they don't have the- as they can see it- as a hotline to support. And that is, it's no one's fault- the lack of resources, you know and there is a lack of communication” (P1)

3.3.1.3 Feeling devalued: Support workers felt devalued by professionals, that their experience was not considered to be worth as much as those with professional qualifications. This led to feelings of frustration and negativity towards psychiatry and a sense of injustice at being made to feel less able due to their role and type of experience.

P3 describes his experience of feeling undervalued by the CIDT and how this relates to being “able” enough as conceptualised through worth and intelligence/knowledge about medication.

‘Well it feels like we, like I said, are maybe we’re not worthy [laughter] of this information you know, we’re not- we’re not er or we- we wouldn’t you know er understand the information that you know is given and er it’s frustration, you know it’s frustrating not to be as- as we people who know him the best, surely- surely they should be coming to us and asking our opinion on- on what- on what we think” (P3)

When asked about whether healthcare professionals at the CIDT understood the pressures on support workers, P4 described how they not only overlook this but also fail to recognise their abilities.

“Well I- I don’t- I doubt it- I doubt it... I think there isn’t always going to be an understanding of what it is exactly we do, therefore as a resource maybe it’s not necessarily- cause you got quite a lot of experience within _____ (current service) team and I don’t think that’s potentially always tapped into” (P4)

3.3.1.4 Being uncertain about complexity: Participants expressed doubt and anxiety around understanding the complexities of the people they support; they voiced these difficulties in numerous aspects of their role but largely uncertainty around psychotropic medication and the challenging behaviour, which it was prescribed for.

Many support workers expressed multiple examples of uncertainty around psychotropic medication. P1 conveys her uncertainty around understanding the effects of psychotropic medication and the impact this had on her relationship to the person she supports.

“I think it was more the subtle- cause I think it’s like say if someone is on medication and they need- they suddenly whenever they saw me, they, they didn’t smile, and they had before- have I done something wrong? Is it the medication, or somebody withdraws, I don’t know, or if somebody really, really- much, much happier, it’s a bit disconcerting?” (P1)

This uncertainty about the expertise they hold can also lead to the idea of psychotropic medication being absent from thinking; P5 doubts his ability to

speaking about psychotropic medication issues to such an extent that he then continues to describe how psychotropic medication doesn't come to mind when understanding behaviour, conveying a sense of ambivalence.

"Erm, I know there's a strong emphasis on medication... I don't feel I've been very helpful in that area because er I'm not well up on it really er I don't really think much of the medication aspect of it really, cause I always tend to think some- well who am I to think like that" (P5)

"I don't think of that due to the medication being reduced, it doesn't really enter my mind really there cause he's quite extreme anyway really, so it doesn't really. It doesn't come into" (P5)

3.3.1.5 Deferring to psychiatry: Whilst support workers were often frustrated with decisions taken by healthcare professionals, there was also the experience of deferring to psychiatry when talking about medication. Disabling beliefs about their role expertise leads support workers to disregard their skills and knowledge as P4 explains regarding the use of medication, which in turn maintains their "disabled" position within this relationship.

"a dialogue on you know- on medication and reduction and you know, erm yeah because I think it's int- you know there's these observations that- that you kind of make and you kind of think well you know I'm a support worker, like I couldn't- I'm probably- I might be a little bit misplaced to make- you know when you've got- you know when someone's being prescribed by someone" (P4).

P8 conveys that her role is not to influence medication decisions, so much so that she rejects the psychiatrist when seeking her opinion. This relationship serves to disable P8 through downplaying her own expertise at the expense of being involved in medication decision making.

"A bit inclined to ask us what we think she should prescribe, and you think I don't know! [laugh] How can I possibly know, really." (P8)
What's it like being asked that question? (DW)

Well it's quite flattering I suppose [laugh]. (P8)

Yeah, why do you think she's ask- what do you think is happening when she asks you that? (DW)

Maybe she's just observing- hoping we're the ones who will be- who observe the side effects or something and then can suggest reducing but I don't you know; I don't really feel qualified to have an opinion about that really" (P8)

3.3.1.6 Lacking medication communication: Support workers felt communication around psychotropic medication was not good enough. Finding out after an incident had occurred or finding out from a third party that psychotropic medication had changed. Support worker's ability to act in response to medication changes is hindered should any decisions not be communicated to them, regardless of their involvement in that decision or not.

P4 conveys how being in an outreach service means that he does not have information about psychotropic medication communicated to him.

"I think obviously you've got er a circle of support, you got different professionals and I- I do feel that- that quite often, erm you know there is information sharing is not always as good as- as it can be and that- that's not just around medication but it includes- it includes medication and if you've got medication that is- is historical and I think you know especially for us because we are an outreach service" (P4)

P2 describes her concerns about a psychotropic medication change she was not informed about following an episode of challenging behaviour with a person with ID that she supports.

"Erm I don't know, erm. I think, we, we will be concerned you know when, when, when the medication had been increase we were quite concerned you know so we, we are never sure is this the reason or are there other things because there are always other things and you need to consider them as well you know" (P2)

3.3.2 Feeling “abled” in prescription role

The following categories represent how support workers experience feelings of “ablement” in their role around medication decision making for the people they support. Feeling “able” in their role was demonstrated through an interpersonal negotiation with psychiatry that had a levelling effect on the power differential between two actors within the system.

3.3.2.1 Feeling part of the multi-disciplinary team: Having a positive interaction with the CIDT and the freedom of access to this team was valued to reduce pressures on their own service. Having closer working relationships with this team meant that support workers felt confident to carry out their role, expertise is shared and felt in a way that offers containment.

P1 describes the benefits of being situated within the same building complex as the CIDT and how this changes her ability to interact with them.

“I think we’re very lucky being in the _____ (current ID service), cause we have access to psychology, psychiatry- quick email, prompt, I could even go up and go “er huh hem”. (P1)

She then goes onto speak about how her service’s close relationship means that she can challenge the team on issues surrounding psychotropic medication for the people she supports.

“...you know there this that confidence from managers, it’s like actually another relationship. With the multidisciplinary team, “oh, I’m really sorry we weren’t aware of this [laugh] you know can we have some more information” and we are quite lucky that we can have that two-way conversation you know, and we all work together” (P1).

P4 conveys how closer access to the CIDT has made him think about relationships with non-medical healthcare professionals who can support them to feel more “able” in the care of people with ID.

“that dialogue is formed [with the psychologist] and then you can really say this is what... I'm seeing and then the same if you've got more of a kind of joined up approach and you've got kind of different voices and different experiences and different angles... it then becomes easier in terms of- for a support worker and the indi- well the you know if- if the support worker's going to have to advocate on behalf of the individual erm then it becomes easier to kind of see whether like a reduction is you know from your obs- you know you feel more part of the discourse I suppose” (P4).

3.3.2.2 Claiming ownership over medication role: A lot of experiences were of being left out or excluded from psychotropic medication decision making. At times however, there were experiences where support workers found agency over psychotropic medication administration or practice. Where most psychotropic medications administered are taken routinely, the prescription of PRN medication places psychotropic medication administration responsibility onto the support worker as the time of administration is not prescribed. Through acquiring a stake, support workers felt “abled” in their medication role and relationship with psychiatry.

P2 describes how she was played a role in psychotropic medication reduction through using PRN medication less often.

“Yeah, yeah, well you know, the person I key work, erm it's gone down quite a lot, we on many occasions have reduced quite a lot quite a lot- PRN for example is hardly ever given now erm there's erm recently so they had been given twice at wo- at home because of her many visits” (P2)

P7 reflects on a previous experience where her support for psychotropic medication reduction was ignored due to risks perceived in other environments, she explains how she now intends to make her stake in psychotropic medication decision making and that she would pass this expectation onto new support workers.

“...if there's no medication can we cope with supporting that erm customer in the erm I don't know communicating or whatever the issues where at that point. But yeah I was- but for a new erm support worker I'd say question, get erm, ask for erm training around erm those kind of medication, not just the day-to-day medications that we need to support our customers with, because at the end of the day we are supporting the person as a whole so it would be good to know as much as possible in order to support them as much as we can yeah.” (P7)

3.3.2.3 Understanding alternatives to medication: With discussions about psychotropic medication, also came experiences and opinions on alternative approaches. These were usually psychological/behavioural approaches to challenging behaviour or mental health problems as well as discussing the benefits of using a holistic approach. Where support workers felt competent to talk to alternative approaches, they felt more “able” in their role around prescribing medication. Understanding alternative approaches to the same difficulty meant that support workers were equipped and enabled to support people with ID and complex needs without having to refer back to psychiatry around medication.

P8 describes how an alternative approach was used instead of psychotropic medication, she recalled how psychotherapy was beneficial for someone she supported where psychotropic medication may have been a first line of approach in her other experiences.

“I think that's probably true, maybe a little bit from psychiatrist of sort of not trying other things, like psychotherapy and, we've had one lady who's had a bereavement erm and instead of changing her medication, she's had lots of therapy, talking therapy; so that- to me that seems like much better to get an understanding of what's going on rather than have some pills, or reduce your pills or whatever it is!” (P8)

P4 conveys how a lack of understanding in behavioural approaches could lead unnecessarily to the overmedicating of people with ID.

“we’re sending through a lot of incident reports, which could be- could be you know linked to kind of- potential triggers could be sensory, escape, attention, tangible, all of these things- not linked to a change in medication but say that individual has just been- had a reduction in medication, but the triggers have got- might not have anything to do with that and- but then that- the information that’s getting cascaded is in an incident report and if the support worker hasn’t been clear in what the triggers and antecedents potentially are then they are going oh well they should be staying on- they should stay on that medication or they should be going up on that medication” (P4).

3.4 Negotiating medication procedure role with provider managers

Where psychiatry will prescribe, the relationship between support workers and care provider managers centres more around procedures (see Figure 4). With regards to medication, care providers hold authority over their procedures and policies of the organisation, this includes putting in place formal training and structures for support workers. Support workers therefore have responsibility, amongst others, for ensuring medication is checked properly, appropriately administered and taken by the receiver. Their positioning to provider managers is experienced through “dis/ablement” but in the context of employing authority rather than professional authority, which asserts itself in different ways as outlined below.

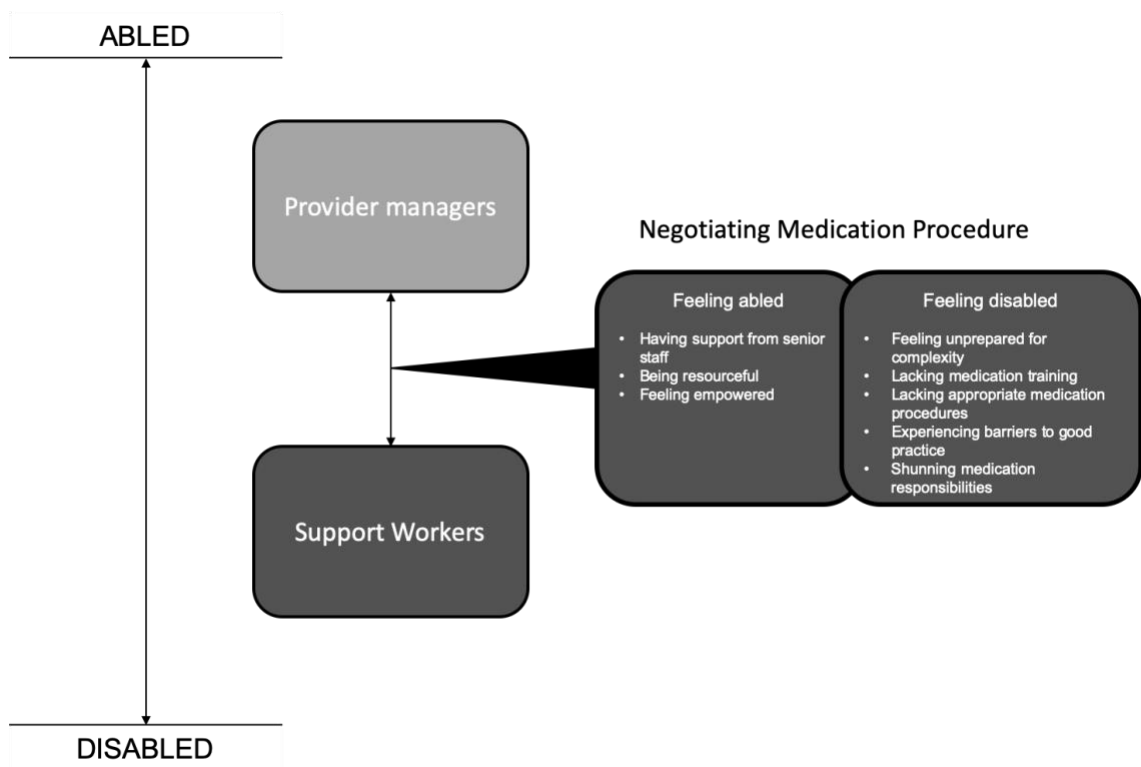


Figure 4: Negotiating care procedure with provider managers

3.4.1 Feeling “disabled” in medication procedures role

By being within the company hierarchy and line management of care managers, “disablement” is felt by support workers more closely to their working environment where deeper relationships can be developed due to more frequent contact. Various actors are represented in the care manager role, where positionality of support workers may change with e.g. senior management compared to care home managers. The latter being more distant from direct support of people with ID, and therefore more “able”.

3.4.1.1 Feeling unprepared for complexity: Support workers voiced their exposure to challenging behaviour and the medicating of people with ID. From the onset of their role, the complex needs of the people they were supporting did not match to their initial expectations of the work. This was expressed as overwhelming to their sense of competency and questioning of the employing organisation’s role in preparing them for this role.

P7 describes how she experienced challenging behaviour from her very first days with people with ID and the effect it had on her. She describes how all-encompassing this effect is.

“I went in with absolutely no background and a little bit of information into- into the job straight away and I think for my first week it was very overwhelming I didn't really know if I wanted to stick in that kind of field and sector, a lot of challenging behaviour from day one that I had never experienced before, erm all over, never- yeah never experienced before erm so yeah I found it quite full on” (P7)

P8 describes how, as a new member of staff she was unprepared for the type of practice she experienced, and how the culture of the organisation was difficult to stand up against

“I was horrified actually, I was genuinely horrified when I worked there cause I thought this isn't really what I- what I was expecting erm, you know there were some staff that had been there for a very long time and think they were just a bit old fashioned in their approach and it was quite difficult to stand up to that and say I think this isn't really the way to do things, cause if you were new you know erm (P8)

The role of psychotropic medication directly was also an experience that support workers felt unprepared for within their role, P4 conveys how psychotropic medication was not something he felt equipped to deal with and the lack of agency associated with this and how he tried to raise this with his manager.

“...I remember very early on I was daunted by the prospect of like medication, like it- it overwhelmed slightly because I didn't have an awful lot of experience er with it er apart- a little bit in the field in- in _____ (country) but not- not a lot erm and I- I remember in a supervision erm speaking to my boss at the time and just being like erm, I was like there's so much medication and I don't really know what any of it does like what- what should I do... (P4)”

3.4.1.2 Lacking medication training: Support workers reported a knowledge gap in medication and complex needs that they voiced as the responsibility of the

organisation to train them in. They experienced however, that psychotropic medication training was lacking, where only basic training, at the most in administration, was given with no further training in understanding side-effects or how the psychotropic medication they were administering worked.

P7 describes how psychotropic medication training is needed in order to have some agency over her role as a support worker, where an increase in understanding could better support her ability to support people with ID and have the knowledge to question the psychotropic medication that may have been prescribed for many years.

"I really don't know, I think [pause] even when we get a new referral, erm yeah we just take the customer as he or she comes in, erm with a support plan of how, what- what the customer- how the customer is at home or what medication they're on, not really questioning anything we just take their customer as he or she is, erm yeah so maybe we need to be a bit more, clued up about medication and then how- why that customer needs it, how long they've been on it, that kind of information would be really helpful." (P7)

P1 voices her desire for medication training that goes beyond administration and into the effects of medication. She compares this to other approaches in supporting challenging behaviour reductions, signifying a specific issue with dissemination of psychiatric knowledge.

"it's like giving medication you get training, if you're giving it there is... we got the supporting people to reduce challenging behaviours... but there isn't to my- I've never been on a training that actually you know proactive- yeah about sort of withdrawals, supporting someone through withdrawal medications, reduction of medications (P1).

P4 makes the point that his service needs to implement further education of support workers around psychotropic medication as a development of the role. He explains how the current lack of education impacts on his autonomy to support someone with ID who is on psychotropic medication.

“I think there needs to be erm- first and foremost I think like, you know better training on you know why the- or the benefits, what er you know what to look for, how to be involved within that- that dialogue and- and also what information should be recorded, you know what I mean and like what- what the support role could look like and- and how it could- how it could benefit the process because I don't think all support staff erm- I mean again it, you know erm I don't think all supp- support staff will be aware of the significance or the importance of- of- of a reduction” (P4)

3.4.1.3 Lacking appropriate medication procedures: Support workers were concerned about the failure of practice, procedure or policy around psychotropic medication itself. This included a lack of implementation of medication reduction policies as well as experiences of poor medication practice and the consequence of this. For some, disagreement about methods and timings of psychotropic medication changes was vocalised.

P8's narrative emphasises the unique placement of medication in creating procedures that vilify honest mistakes. This suggests that procedures act to gain compliance through fear rather than understanding and learning, something P8 feels is counterproductive.

“cause if you make mistakes in most areas, they're usually fairly understanding about it, but not with meds, no it's a sort of scorched earth approach, which actually doesn't help, it makes you so nervous” (P8)

She continues to explain how this policy creates a culture of fear that reduces transparency, this environment serves to create a feeling of “disablement” for support workers in their role around psychotropic medication.

“I think it starts a cultural of trying to cover things up for a start, because people are scared, erm and I think that's very dangerous actually, very dangerous, you can't sort of go and say look I made a mistake here, can we talk about how we can, as a team make sure that never happens

again or something, it goes straight to _____ (division of current service) and goes to their, you know, disciplinary panel” (P8)

Further procedural difficulties were identified by support workers when it came to reductions in psychotropic medication. Whilst generally supportive of the idea, support workers remained critical as to how this had been managed by the organisation. P4 describes the poor timing that his service agreed to a medication reduction as this coincided with a major transition for the person with ID; he concludes by conveying the impact on the person he supports and subsequent medication management.

“someone else I’m supporting at the moment, who- you know there- there’s- there’s a reduction at the moment but it’s right as he’s gone into crisis and he’s going to be moving- he- he had to leave the family home- it’s being very traumatic for him, it’s been incredibly traumatic for the family, as well and erm I think his medication has fluctuated quite a lot” (P4).

Most support workers had never heard of or received information about formal initiatives for medication reduction (i.e. STOMP) and the subsequent expectation that reduction be integrated into the service’s role in monitoring medication. Support workers have largely been absent from these discussions whereby senior managers may be aware of the STOMP initiative, but this had not translated to support workers on the ground. P7 articulates her views on STOMP after being informed about it during the interview.

*“I suppose erm, does it feel like STOMP is- I suppose well, present or yeah or- or beneficial or erm- (DW)
-Yeah, I would like to look more into it, and I think that erm showing that awareness or highlighting that awareness of erm I don’t know an initiative to kind of- kind of get people thinking about erm, medication and- and how it can be reduced (P7)”*

3.4.1.4 Experiencing barriers to good practice: In addition to formal policy and procedural issues, support workers also reported difficulties within the staff

team and between them and management as impacting on the functioning of the services they work in. Experiencing barriers within the organisation was felt as “disabling” to support workers, where cultures or relationships with certain staff members fostered a sense of detachment and isolation.

Medication in itself was interpreted to have created a culture of mistrust where support workers were suspicious of the organisation’s motivations for keeping the people they support on psychotropic medication. P8 describes how, in her experiences, staff became complaisant with medication administration, she explains how there was a resistance to change around the way in which people with ID were medicated.

“the people who had been there for ages sort of, picking up the MAR (medication administration record) sheet, not matching it to the blister pack and you know, oh well you know, it was just a bit haphazard, this is why- we’ve done it like this for years we’re not changing you know” (P8)

P6 describes the futility of raising issues of psychotropic medication side effects, which suggests a disinterest in listening to support workers’ concerns for the people they support. She goes on to comment that this raises a broader issue about the value base of an organisation, where an attitude of short termism currently prevails.

“I think it’s some people become more sleepy, say with a person who has epilepsy they increase the medication and she is very sleepy now, challenging? It’s no good.” (P6).

“So, I think, quality is very difficult to measure, and it only- it’s only seen with the long term, it’s not just because he’s doing this today great or tomorrow. I think it’s a process, a process is very difficult to quantify yeah, so I think actually it’s the mental structure that we need to change a focus and it’s about quality” (P6).

3.4.1.5 Shunning medication responsibilities: The expectations put upon support workers came across as undesired and with discomfort. Support

workers experience conflicting pressures, they must carry the responsibility for medication but without the knowledge or confidence to do so. This was perhaps the most pronounced experience of “disablement” where support workers felt paralysed in this expectation.

P6 describes her relief to be in a new role where regular psychotropic medication administration is not carried out. She makes it clear that psychotropic medication is something she would rather not be a part of, in so far as it goes against her stance on medicating people with ID.

“I think it's the worst thing- I think it is the worst thing and I have done- I have to do PC [personal care], and I have to feed people I have to clean, and I think it's the worst thing. I'm so relieved in this service we don't, I don't find it, anything like that and personally because I have also this posture around medication, which is very strong. So actually, I feel disgusted to give these people medication. (P6)

P8 describes her shock at her new responsibilities for administering medication and how this was not made clear to her by her employing organisation, suggesting that it was portrayed as less responsibility than she experienced it.

“I was horrified about the- the level of responsibility the staff had, without much training because I did the job for six months and had no training whatsoever erm, that was horrifying, because they don't tell you that in the interview, they say do you mind- being you know, assisting with medication and you imagine it's just passing a glass of water to somebody” (P8).

3.4.2 Feeling “abled” in procedures role

Support workers experienced a position of “ablement” where procedure and administration complemented rather than contradicted one another. Support workers negotiated this either through management showing flexibility with procedures or support workers drawing on their own resources to bridge this divide.

3.4.2.1 Feeling empowered: There were instances of support workers being or becoming aware of psychotropic medication and its changes. Support workers become more aware of psychotropic medication at different times in their career. Regardless of time, the emergence of this knowledge led to a sense of agency where support workers felt more “able” in the role.

P1 explored her new knowledge of psychotropic medication and how she imagined further training would support her in her role around medication, she conveys how this would mean her opinion is taken on board.

“if I know that, how it works, I will have actually- that means I've done this training I have more responsibility, and I have an accountability, of the process, in my role, it's not just done to me you know and I'm not saying I should be able to say they should or they shouldn't, cause that's not my role but actually my views as a support worker and people who know the person's views should be considered” (P1)

P1 then goes on to reflect that by having greater medication knowledge, she could support in positive changes such as reducing the amount of psychotropic medication that the people she supports are on.

“That's where the starting point for I think- thinking is like that person we don't want that person on [medication] forever, how are we going to give them the best chance of getting off it as soon as possible” (P1)

Support workers voiced a change in medication procedures or feeling trusted when individuals in senior positions came alongside them in their work. Empowerment was experienced as resisting structural factors within their organisation which acts to “disable” support workers, who in turn, defer more to psychotropic medication and those who hold most control over its delivery.

P7 describes the differences between her new and old role in the education sector, she explains that whilst there are some personal benefits

"[on having a focus on health needs in new role] Definitely a pro here, because erm we're more involved in- in erm the health and the needs of our customers erm, I guess the pro in- in the school setting is someone else is kind of dealing with the health side and we're just focused on the education side but then the con of that is, we know that the health issues may affect how the customer- er the student is learning" (P7)"

P8 describes how a supportive manager has meant she feels empowered to contact professionals and give feedback to psychiatry about psychotropic medication.

"...in this service, our managers expect us to do that, which is the first time ever- I've ever experienced it. Normally you'd just report it to a manager and then they take it up, _____ (manager) expects us just to go direct, which is quite nice to know you've got that trust." (P8)

"Yeah absolutely" (DW)

"Because some managers would be like- what- what are you doing?"

"what does it feel like being given that erm-" (DW)

"-It's quite scary but it's also quite- I- I like it, yeah. I mean, being taken seriously and like your opinion matters" (P8)

3.4.2.3 Having support from senior staff: Support workers spoke of having support from their wider workforce, and the importance of having them there to reach out to when needed, trust and support was important from both peers and those in supervisory roles.

P2 explains how she reached out to senior colleagues in order to cope with the impact that psychotropic medication withdrawal had on the person she was supporting.

"How did you manage that withdrawal of the diazepam for that person you were working with?" (DW)

"Well, I brought it up with the people I was working with you know, my, my supervisor at the time my, my manager and, and erm they couldn't

understand it but what we didn't know was is this actually the right way to do it" (P2)

3.4.2.4 Being resourceful: Support workers conveyed their ability and desire to learn regardless of the opportunities not afforded to them. As the area they felt least trained in, medication knowledge was often sought, be it from the internet, from willing professionals or from medical books e.g. the British National Formulary (BNF) handbook for guidance on medications prescribing, dispensing and administering (Joint Formulary Committee, 2019). Where procedural issues felt "disabling", drawing on their own resources helped to reclaim a sense of "ability" within their role. This often occurred when medication had become particularly salient, such as during a change.

P3 describes how, in the absence of training, he has managed to acquire information about psychotropic medication himself.

"I think I say- you know as I said earlier I think you know I've managed er you know to pick up information here and there, so I've- I've- I've- I you know have a greater understanding of the meds and- and how and what they get used for" (P3)

P4 explains how he had a desire to learn more about psychotropic medication and sought knowledge from medication handbooks, he then goes on to explain how later on in his career he began to think about medication more critically.

"I want to know more about this and so I think off the back of that purchase- I can't remember I was looking at in in the office just now it was erm like, the BM- is BMI guide to" (P4)

"-BNF?" (DW)

"That's it yeah, guide to like drugs and medicine do you know what I mean, Yeah, erm and so I kind of took a kind of active kind of interest in it then but I think in terms of really kind of beginning to question the- the role that it plays and perhaps whether it's being overused that's something that's much more recent" (P4).

3.5 Negotiating the caregiver role with people with intellectual disability

In contrast to the service levels contexts, the relationship between support workers and the people they care for differs significantly. With the CIDT/psychiatry and care providers, support workers must deliver on recommendations or instructions given to them. For people with ID, support workers must negotiate their care giver role through ensuring adherence to medication or responding to behaviours they perceive as challenging. Unlike the service level context, support workers did not voice their role as tightly to medication despite its focus within interviews. The model suggests that medication decision making from above can be felt in broader aspects of the caregiver role in supporting people with ID.

As “ability” permeates the ID system, support workers are positioned as more “able” than the people they support, this is in contrast with care managers and healthcare professionals where the reverse is expected. Support workers positioning of “dis/ablement” from a position of power was experienced in a number of ways where psychotropic medication was either directly or indirectly involved in this relationship. “Ablement” was associated with a holistic view of the person they support and empowering the person with ID through their support. Psychotropic medication permeated feelings of “Disablement” both in its witnessed effects on the people with ID or as a solution to difficulties that support workers struggled to conceptualise in another way.

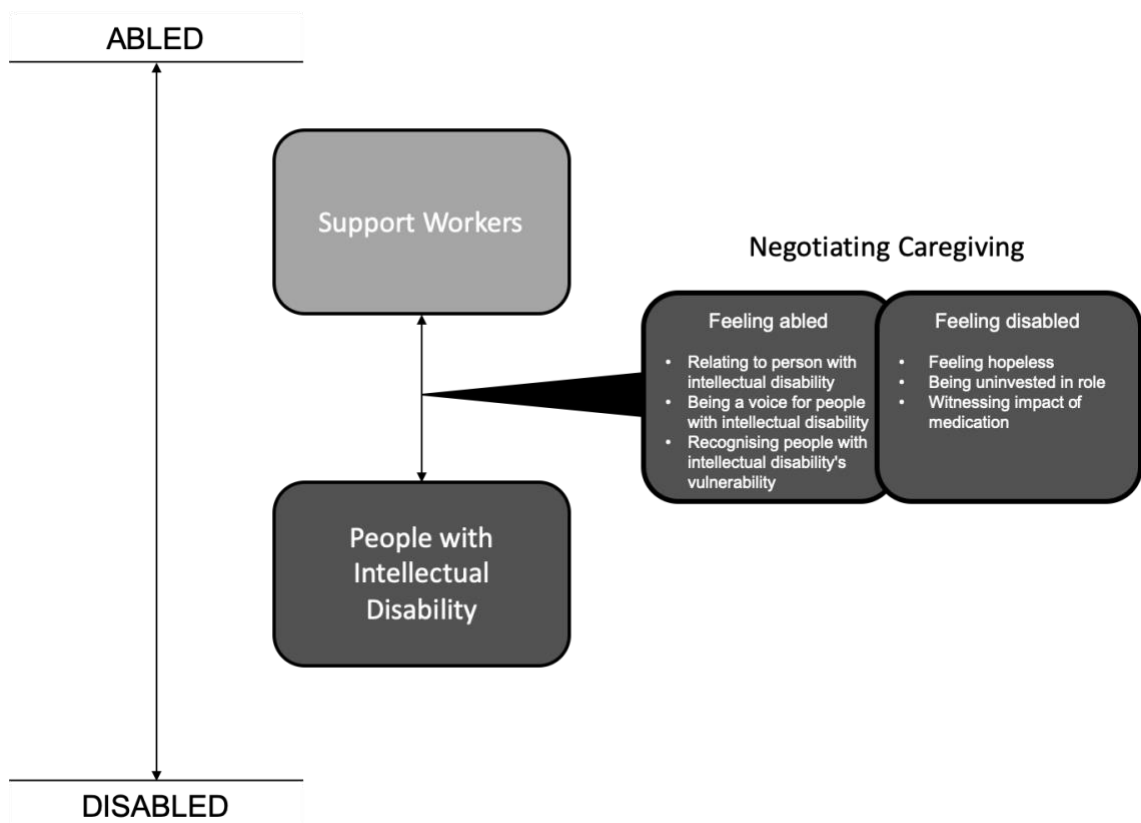


Figure 5: Negotiating caregiving with people with intellectual disability

3.5.1 Feeling “disabled” in caregiving role

The caregiving role would typically be seen as positioned as more “able” than those they care for. Despite their relative position of power, support workers did feel “disabled” in the negotiation of care with people with ID, where “ability” conveys a competence to care for, when this is contradicted within the support worker-person with ID relationship, this is experienced as “disabling”.

3.5.1.1 Feeling hopeless: At times, support workers experienced feeling hopeless for the people they support, this was demonstrated through their perception of disability in people with ID.

P5 describes a visit from council workers where they try to ask a person he supports about his placement, his inability to be hopeful is demonstrated through his conceptualising of the person with ID not being “able” to offer something to professionals.

“...he couldn't answer it, he just kept on going swimming, swimming and he wanted it's three more days till swimming really there. So, I knew they wouldn't get much from him really there, you're not going to get much from him really there” (P5)

Without a sense of personal hope for the person he supports, his experience of “disablement” in this case, lends itself to apathy about any interventions that might be put in place. It can be seen how a psychotropic solution for any difficulties can become more readily put in place where apathy prevents more holistic thinking.

“I don't really play any part in it really there. Obviously, [if] there was something noticeable, really extreme, really there, then obviously it would be er, we'd obviously refer it back to the doctors really there and they'd probably put him on a higher dosage or return the table”. (P5).

3.5.1.2 Being uninvested in role: The nature of support work is transient, people with ID regularly have relationships that come and go, which they have little control over. The relevance of the transient worker to uninvested care is twofold. Firstly, the worker's temporary role within the service may result in a lack of time or other resource to build a meaningful association with the service's users. Secondly, the very existence of transient workers suggests they occupy a system that is not invested in their role and that this is felt by the worker. This positioning effects support workers' relationship with the people with ID, a distancing both emotionally and in knowing the person they support.

P4 speaks of the transient nature of the role impacting on the quality and breadth of skills sets that reside amongst support workers.

“I don't know, I think you've got some people that are- that have got like a value base that is- is very well suited to it and I think you've got other people that are perhaps less, and I don't know quite how to word it but you know there's like a bit of a disparity in- in kind of skills sets and things like that” (P4)

He goes on to explain how this role transience and uptake of temporary staff can impact on their role around psychotropic medication where the relationship with the person they support is lacking.

“you’ve got someone in that- that’s covering a session you’ve got a lot of bank work you know workers that are just coming in to support someone, they know nothing about this individual, so how can they know anything about the medication, or the importance of the reduction in it” (P4)

P5 explores his own sense of transience, his feelings of “disablement” come through in how he sees his work, conveying his disinvestment and perception of his relationship to the people with ID.

“I wouldn’t say I love the job but I- I can deal with it now really there. It’s a stop, for me personally it’s sort of a stopgap until I get something else outside really there. I- I don’t feel like I benefit the service users, I’m just here to stop them.” (P5).

3.5.1.3 Witnessing impact of medication: Support workers are in a position to receive direct evidence from the people they support of the impact that psychotropic medication and its withdrawal has on people with ID. Support workers expressed the disabling side-effects of psychotropic medication on the people they support and how this reflected on their “disability” to engage in their role as they usually would.

P4 explains his experience following an increase of psychotropic medication for a person with ID that he supports.

“his presentation has changed into like they don’t recognise- like he’s not communicating and he- yeah his presentation has- has completely changed, his interaction erm with- with family members is- is non-existent you know he’s completely disengaging” (P4)

P3 recalls witnessing the psychotropic medication withdrawal for one of the people he supports. He conveys how this change in behaviour restricted his own sense of how he can support this person.

“maybe at times it makes us more risk adverse if we’re- if we’re unsure how the individual is going you know to respond to something maybe we’ll think, well let’s not do that- let’s not do that, it might be a bit too risky and it just- it just erm yeah it moves- moves the goals posts a bit, you know what I mean? (P3)

3.5.2 Feeling “abled” in administration role

Feeling “abled” in their administration role, support workers would bring the needs of the person with ID into their awareness. “Disablement” was felt when support workers could not see ability in the person they were supporting. Support workers felt “able” however when they recognised ability in the people they support and conceptualised disability as something that is changeable with their support.

3.5.2.1 Relating to person with intellectual disability: Support workers felt “abled” in the care they give when underpinned with a meaningful relationship. Through relating to people with ID, richer narratives could be created that moved beyond “disability” and medication.

P6 describes how she values the contribution of the people she supports and that she rejects the one-sided narratives about “giving care”. She deconstructs the concept of serving others, where instead serving operated within the interpersonal space between two people. She therefore offers a means of serving that challenges power differentials and aims to empower both within a relationship.

“...you can serve with submissiveness in any role in the world, or you can serve with power, yeah. And that’s the meaning for me... is to provide a service from my power- from my place of power, yeah. Erm and that’s why I find it meaningful because it’s a group that is in need and

they always give me back- they always give me feedback they always give me back, always and that's good" (P6).

P1 speaks about how medication reductions can impact on relationship building, she explains how relating to an individual's emotional expression, that may increase when medication is withdrawn, can build a sense of commitment and trust not despite, but because of challenging experiences, a feeling of authenticity in the relationship.

"the less medication that is needed for the individual, you get that fluctuations more, you get the high, you get the lows. That's what- I suppose that makes it stronger... actually knowing that someone is still there for you after you've had a real difficult time, you know and there's someone there, that would build a relationship stronger, we hope." (P1)

3.5.2.2 Being a voice for people with intellectual disability: Support workers defined their role through advocacy. Being positioned in this way, lends itself to valuing and projecting the needs of the people they support. By advocating, support workers negotiated their care role with people with ID where "ability" and "disability" does not become an assignment between two people. Support workers felt "abled" in relationships that recognise the abilities of the people they support, and seek to challenge the impact of "disability" on people with ID.

P4 explains the role of advocating for the person he supports around psychotropic medication, and how a lack of knowledge about psychotropic medication impacts on this, nevertheless he continues to try to put this to those in medical decision-making roles.

"In terms of advocacy it is just through kind of sharing- sharing the information that we have and making sure that that is- that's relevant to all of the parties- I don't- I think in terms of my... level of kind of understanding... I don't have the level of training I feel to kind of- to really say with any conviction- I might have my- I might think hmm that might be down to a change in medication but I- I think in terms of kind of an advocacy role I would share that information" (P4).

P8 reflects on the people she support's ability to have a voice around their psychotropic medication and her role in advocating for them.

"it's kind of a direct experience of yours in terms of- erm having to do that advocacy and wondering what it's like to be in that person's shoes... I wonder how that impacts on erm, on medication being given out then... (DW)

Yeah well, I mean you'd have to be quite, I mean there's a person here who's perfectly able to say whether he thinks he's having too much or too little, erm but [sigh] I think the rest actually are fairly passive about it, if that's what the doctor says, or the psychiatrist says and so many of them have come from institutions as well, I think they got- got kind of used to people telling them what to do" (P8)

3.5.2.3 Recognising people with intellectual disability's vulnerability: Support workers reflected on how people with ID represent an oppressed group within society and viewed their role in challenging the potential misuse of interventions such as psychotropic medication.

P6 raises her concerns at the use of psychotropic medication to serve the interests of businesses rather than the people she supports. She conveys her scepticism about multiple use of medications.

"from what I have read I think medicalisation, is just a business- it's just a business. Cause they are producing more medication for people that they know they give side effects, but they have the medication for the side effects as well isn't it, is that not business, that's a lovely business." (P6)

P3 justifies his use of the term chemical restraint to explain psychotropic medication as serving people other than those with ID, he concludes by placing his own role in promoting alternative approaches to medication as a first line of intervention.

“And it’s quite a powerful word isn’t it, chemical restraint, do you think it’s- do you think it’s a word that gets used much or is understood in that context?” (DW)

Not enough... call it as it is and I think at- at times that is you know exactly what it is and I think... it’s always er looked about- looked upon or framed as- as this is what they need but actually is it what they need or is it what the- what the you know people around them needs? You know, and erm and again I’ll go back to it again but the maybe we need to have a look at other ways of supporting the individual and then you use the- use the drugs, medication as a last resort, not the first. (P3).

3.6 Summary of analysis

This model demonstrates an understanding of how a support workers’ position in the ID system impacts on how they negotiate their role in the relationships they have with other actors in that system. This model has largely explored this role within the context of psychotropic medication yet cannot separate itself from the broader role of support workers, and so conceptualises a small part of a much wider system and activities.

The relationships that support workers have with other individuals within ID services largely created a sense of “disablement”. Whilst this feeling was associated with many roles involved in supporting people with complex needs, psychotropic medication was experienced as a role where support workers felt particularly “disabled”. Feelings of being “able” were also experienced, this was associated with a greater sense of agency within the role. In addition to feelings of “dis/ability” within their relationships, support worker’s accounts also suggested how ability is constructed across ID services. Where feelings of “disability” in individual relationships can be reflected against how disability is constructed within the system to understand how current roles are maintained.

This model adds to the existing frameworks around inequality such as the “social graces”, which demonstrates how individuals may be privileged or marginalised through various aspects of difference (Burnham, 1992). This construct of “intersectionality” was historically applied to demonstrate how

woman may be additionally disadvantaged in terms of race (Crenshaw, 1989) and later to recognise broader, multiple disadvantage (Burnham, 1992). Criticism can be made of the application of intersectionality, which could ignore or “miss” the complexities of disadvantage beyond a simplistic multiplication approach.

The “negotiating dis/ability” model attempts to conceptualise this complexity, where other frameworks do not, by explaining how those with power over another may also be subject to their own experience of oppression given the very role they are doing. This is particularly important for health care professionals who work with systems surrounding people with ID because it is typically the person with ID who is seen as the identified patient or the identified “problem”. To management or health and social care professionals, it may be the support worker who is seen as the identified “problem”.

This model allows clinical psychologists, who increasingly provide consultation to professionals within CIDTs, to recognise how the support worker role represents a marginalised group. This is the case not just in terms of the common demographics of its workers (class, gender and race), but the role itself and how this relates to “ability”. This allows for exploration with management and professionals of the support workers’ voice and how it is held within the system where professionals may maintain “disability” narratives about them. The “negotiating dis/ability” model can act as a framework for facilitating conversations that seek to nurture experiences of feeling “able” and understand those experiences that “disables” support workers in their role.

4. DISCUSSION

4.1 Overview

In this chapter the findings of this study as conceptualised within the “negotiating dis/ability model” will be reviewed. The model will be discussed and how it relates to existing theory in the literature. The findings will be explored in how they can contribute to new research perspectives in the field of ID. There is

currently no known model that accounts for the role that support workers play in the psychotropic medicating of people with ID. An emphasis will be placed on the utility of the knowledge constructed from these findings, and for who this knowledge best serves. Implications and recommendations for improving services for people with ID will be discussed. The research aims will be critiqued, and the method used evaluated on how the answers are demonstrated from the data categories in which they were constructed.

4.2 Interpretation of the model, implications and recommendations

4.2.1 Placing the model in the context of existing literature

This study contributes to the extant research through recognising “dis/ability” within different relationships in the ID system as experienced by support workers. It provides an understanding of how the psychotropic medicating of people with ID operates within this system and the support workers role within it.

The views and experiences of support workers in negotiating their role across a system chimes with the limited research that has sought their views. Windley & Chapman (2010) explored the key roles that support workers developed within ID services, they identified the same three groups as was constructed in this study’s model. They identified similar themes around support worker’s recognising the vulnerability of people with ID, taking a trial and error approach in the absence of appropriate training and a desire for closer connections with the CIDT.

It is of note, particularly given the paucity of support worker experience in the ID literature, that this model can have broader implications across multiple settings where support is largely given by paid carers. Dementia care, people with long term physical and/or mental health conditions, brain injury services, and residential units for children all have a high presence of paid support. Cross over is comparable given the very similar medication reduction policies introduced for individuals with dementia (DH, 2009a) and young people, aptly abbreviated to STAMP to relate it to its adult ID sister policy (NHS England, 2018). Like in the field of ID, research into the views and experiences of support

workers of other client groups is sparse. The limited research literature does however show how feeling “abled” may impact on job role and wellbeing, suggesting that this could be applicable to other fields. Dementia care workers can experience stress in relation to job and client characteristics, where training is considered to support these difficulties (Brodaty, Draper, & Low, 2003). Where care workers perceived themselves to be competent in providing dementia care, more sensitive attitudes to their clients and higher job satisfaction was experienced (Zimmerman et al., 2005).

4.2.2 Support worker “dis/ablement”

The concept of ableism represents discriminatory actions towards people with (intellectual) disability who are perceived to be less “able” mentally/cognitively. There is some confusion between ableism and disableism, and whether they are interchangeable. Where disableism concerns itself with “others”, framing this focus of action towards them (Campbell, 2012), ableism broadens the concept to mean:

“a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human” (Campbell, 2001 p.44).

There is a small but growing literature on the experiences of people with ID though the lens of ableism, this is particularly prevalent in terms of ableist discrimination for people with ID to have sexual relationships (Gill, 2015; Rohleder & Swartz, 2013) or indeed the complex issue of mental capacity (Simplican, 2015). In fact, much of the recent exposés around abuse and the subsequent legislation has come from a position of tackling discrimination against individuals with ID based on dis/ability.

4.2.3 Top down “dis/ablement”

This study is the only known of its kind to conceptualise how an ableist system negatively impacts staff working within it who do not have a label of “disability”. Experiencing ableism by-proxy has had some exploration in how it affects close family members; Rieck, Shakespeare-Finch, Märtsin, & Knox's

(2019) studied how the complexities of being a mother for a child with ID were filled with a need for belonging, where a sense of community was not felt and the hardship this brought. Through exploring ableism within a disability focused system but to those not deemed to have a disability, this could act as a stepping stone to recognising how ableism pervades all systems (society), and that ID services are a further reflection of this (Wolbring, 2012).

By bringing a cultural ableism perspective, the experiences that non-disabled people face, can be understood where certain forms of “dis/ability” are expected of them from others in the system. The model constructed in this study reflects the social & post-modern model of disability that counters categorised, biomedical explanations of disability, instead placing “disability” with the social system (Charlton, 2004; Haydon-Laurel & Nunkoosing, 2010). Where family members have experience ableism, this research has shown this to be the case for paid support workers also. They talked about how they may not be seen as worthy of information about psychotropic medication and overlooked for training. Ableism has extended to support workers due to their close proximity to the people with ID in a comparable way to family members (Rieck et al., 2019).

4.2.4 Bottom up “dis/ablement”

The “negotiating dis/ability” model also conceptualised the support worker relationship with the person they support and how ableism can be understood from the support worker’s perspective. Whilst feeling “abled” in ways of advocacy, relating to the individuals and recognising their vulnerability within the system, feeling “disabled” came across from witnessing the impact of strong medication on the people they support, feeling uninvested and hopeless.

Similarly, the literature drawn from family experiences of ableism can inform support workers’ experience. Friedman (2017, 2019) explored the attitudes of siblings and other family members of a disabled person. She found that siblings with a disabled brother or sister had very low levels of explicit prejudice, recognised by their strong commitment and deep relationship. Implicit prejudice however was high and is conceptualised as the consequence of an ableist society combined with a different disability experience than their siblings.

Neeley-Barnes et al (2010) describe how families can be both the object of discrimination from their community whilst also trying to manage their own feelings about disability, which may include internalised ableism. They found that when empowered, parents were able to use advocacy and education to change the environment for their disabled child. Where support and inclusion were lacking, parents may be more likely to act in ways that reinforced ableism. From the model constructed, similar processes are thought to be occurring for support workers, where there is a need to engage with emotional reasons for oppressive relations (Ellsworth, 2005).

4.2.5 “Dis/ableing” roles and relationships

This study’s model understands “dis/ablement” experienced by support workers negotiating their role with others as being located interpersonally between the support worker and another, it is relational. Like families, ableism permeates the relationships that support workers have within a system that has a high disability focus. The model constructed in this study demonstrates the multiple groups that support workers must negotiate with in the system and the complexity of their role.

4.2.5.1 Dominance of individualising approaches: medical and behavioural approaches to challenging behaviour locate problems within individuals with ID, which neglects the relational and interconnectedness of experience within these systems (Haydon-Laurel & Nunokoosing, 2010).

Where individuals with ID often have their difficulties individualised, so do support workers. This clearly represented within the staff burn out literature. Many of the studies reviewed in section 1.4.2 conceptualise burnout as a problem within support workers due to external and internal pressures, leading to solutions like resilience training, stress management, mindfulness or finding a “support network” (Gray-Stanley & Muramatsu, 2011; Nevill & Havercamp, 2019). Skills teaching often occurs with non-medical approaches to supporting people with ID. Difficulties with this approach can be extrapolated from Embregts et al.’s (2017) work on applying self-determination theory (SDT), which formulates a supportive environment that values autonomy to improve how staff interact with the people they support. They found that support

improved with regards to attending to a client's needs for autonomy and competence. SDT, however could equally apply to how home environments affect all those within them. The findings from this study would question how autonomy can be supported in people with ID if support workers themselves lack autonomy in their own role.

Positive behaviour support has recently developed more complex models for understanding the organisational context of challenging behaviour. Coined as "systems-based" PBS, its application has had promising results for challenging behaviour reduction and quality of life (Hastings et al., 2013; McGill et al., 2018). Applying PBS to a system does not however mean it conceptualises difficulties systemically. Its structured approach, behavioural underpinnings and neutral expert positioning does not account for the relational role negotiations and the "dis/ablement" that occurs within it. In these two examples, whilst the work is encouraging for its positive outcomes, the approach however shifts the individualising of the "problem" from the person with ID to the people supporting them, advocating the same kind of "doing to" approach, which has been so widely criticised for disempowering people with ID.

4.2.5.2 A radical systemic approach to support workers: Utilising systemic thinking and approaches in ID services can help to raise the voice of people with ID where it may not usually be heard, changing the language of "them" to "us" (Baum & Lynggaard, 2006). The findings of this study offer novel insights where systemic approaches can broaden their intervention, where the "identified patient" may not be the only "identified problem". The systemic approach understands support workers as being in mutually influencing relationships, systemically conceptualising the service system allows for service change. Where approaches attempt to support people with ID by focusing on "fixing" staff, the problematising narrative continues within the organisational culture reducing the likelihood of real change for people with ID. As Mason (2000) puts it, "culture eats strategy for lunch" every time (p.14).

Systemic approaches can address cultures of dis/ablement that this model represents within ID services. Haydon-Laurel and Nunkoosing (2010) used a systemic approach to move from individualising challenging behaviour within

the man with ID to coordinating the relationship between the man and his support workers. Systemic approaches achieve this through the positioning and questioning of the therapist; *“why is the relationship being formulated as a problem now? For who is this problem? Who is most concerned with these events and people?”* (p.75). These questions allow for the exploration of problematising for any individual within the system.

4.2.5.3 Clinical psychology and the system: Clinical psychologists are often positioned in ID services to provide psychosocial interventions and are increasingly becoming involved into clinical and consultative leadership roles (BPS, 2017). Their understanding of multimodal approaches to distress and working with individuals across the system, places them in a key position to work with “dis/ablement”.

Using systemic consultation with care managers Fennessy et al. (2015) found that they experienced lower levels of stress and higher perception of workplace functioning following consultation; they reported a reduced sense of “stuckness”, a greater sense of agency of change and perspective taking. Systemic consultation could therefore be a useful approach for fostering agency and empowerment in support workers, and challenging narratives of “disablement”. Systemic working with healthcare professionals and provider managers could also benefit support workers and people with ID. By having a time and space to reflect on challenges and work in the context of support workers’ experience, those in senior positions can better understand their own relational negotiating with this staff group. Instead of doing to, professionals can understand how they do not act on the system neutrally but are part of it, where they can make a change that makes a change (Pote, Mazon, Clegg, & King, 2011).

Employing a systemic approach does not however mean abandoning the benefits of PBS, as an integrative profession, clinical psychologists can take a pragmatic approach that honours both models. Systemic practice does not have to be rigidly shoe-horned into PBS to make it compatible with behavioural approaches, in fact the PBS method and its behavioural strategies could

function adequately and more efficiently within a pluralistic systemic framework (see *approach-method-technique* Burnham, 1992).

4.2.6 Implications for psychotropic medication usage in services

While this study acknowledges the broader “dis/ablement” of support workers in their role across ID services, the focus on psychotropic medication as a particular aim raises implications for how this may affect usage in services.

Experience of “stuckness” around medication was a common theme for participants in this study. Support workers can often struggle with what is in the best interest of the people they support. Support workers have been found to make day-to-day *ad hoc* “best interests” decision for the people they support by drawing on their own values and experiences which may not sit neatly with, for example, the Mental Capacity Act 2005 (Dunn, Clare, & Holland, 2010). The “negotiating dis/ability” model recognises this paralysis particularly with respect to psychotropic medication, where support workers sit between the challenges they face in administering medication to the person they support and the challenges they face in relation to incorrect administration from higher power structures that impose policy/legislative authority. Trying to attend to their own role in two directions was experienced as “disabling” in their role.

Experiences of support workers in this study suggest that they are not being adequately involved in the medication process, largely as a result of exclusion from major decision making. Whilst support worker’s views on medication are limited in the literature, the views of parents has been recently studied by Sheehan, Kimona, Giles, Cooper, & Hassiotis (2018) who found that like support workers in this study, inclusion was felt to be of significant importance, themes of being marginalised and lacking in information were also prominent from their findings.

Whilst medication reduction continues to be of national interest, it has to be recognised that medication is likely to stay a part of the lives of people with ID for some time. Effective use of medications when they are prescribed therefore is vital. (Nabhanizadeh, Oppewal, Boot, & Maes-Festen, 2019) found that systematic medication reviews can assist in reducing medication-related

problems in people with ID such as unnecessary polypharmacy and medication errors.

4.2.6.1 Clinical psychologists and psychotropic medication: As further attempts are made to improve the STOMP agenda, clinical psychologists play an important role in developing and maintaining alternative, non-medical/psychosocial approaches to challenging behaviour and other manifestations of distress.

Proper assessment and formulation should precede prescribing of psychotropics in people with ID, this should also require input from a range of individuals including carers. By working with the system, clinical psychologists can play a key part in orchestrating current guidance, which recommends that communication is paramount when prescribing for people with ID (Unwin & Deb, 2010).

Reductions were experienced by the participants in this study in a way that current auditing and medication trials cannot conceptualise. The “negotiating dis/ability” model is useful in explaining why there is still an overuse of medication and poor review. The complexities around medication reduction was experienced as destabilising to the care that support worker give. This can have a negative impact on people with ID, where poorly communicated reductions may place them at greater risk of harm or further restrictive practice. Without the “buy in” from support workers, reductions may fail. Although the extent to how much drug use has changed recently is yet to be evaluated (Branford, Gerrard, Saleem, Shaw, & Webster, 2019a), experiences in this study found STOMP was unknown or caveated with reduction issues. There needs to be an approach that can formulate and recognise the structural positions of power, particularly around the “ability” of support workers to contribute and its consequences on medication reduction.

Robinson (2019) calls for people to be empowered to participate in and challenge the decisions made by prescribers, where this was noticeable in his survey, it had a transformative effect, improving the lives of people who have

been on long term psychotropic medication and experienced its deleterious effects.

4.2.7 Recommendations, towards a post-normalisation future

The findings and implications from this study require a pragmatic response to create a greater democratising of social care where a normalisation approach has not made the gains originally expected where its operationalising within broad based policy has moved it away from its original inception (Wolfensberger, 2011). Although leading to some positive changes in treatment of people with ID, this study supports criticism that approaches have often appeared too corporate and top down, which ignores the needs of staff that work most directly with people with ID.

Mesibov (1990) was an early critic of having community care without an understanding of the social context of services, he criticised the theory as lacking in its application to complexities outside of the institution. He stated that a home doesn't automatically lead to skills and wellbeing where individual client need can be distracted from a push to normalise, he questions whether "integration" at all costs is even appropriate. This study calls for pragmatic pluralism, which recognises an overreliance on skill based individualised approaches to challenging behaviour and medication. There is much needed utility in applying relational based, systemic approaches to supporting people with ID and complex needs where psychotropic medication is being taken. McGill, Bradshaw, Smyth, Hurman, & Roy's (2014) work on "capable environments" has begun to recognise the role of the whole system in maintaining challenging behaviour and staff experiences of this. Whilst support worker's needs of professionals have been outlined, people with ID too, want professionals to be adaptable, able to communicate and work with the whole support network (Weise, Fisher, Whittle, & Trollor, 2018).

Bigby & Beadle-Brown (2016) investigated the culture that resided within group homes that were "better" than others in accordance with *What Does Good Look Like* guidance. Power holders were leaders and aligned their values with support staff and the organisation. Through sharing responsibility to empower

staff, a cohesive and respectful environment was created that can be enabling for residents and motivating for staff.

The past decade of abuse exposés has shocked policy makers into action, an unfortunate consequence has been that support workers as a group, may be defined by those that are abusive and make headlines. Kumashiro (2000) suggests that the binary division of e.g. ‘oppressor and oppressed’ is too simplistic, resulting in the drawing of sides, the experiences of support workers in this study support this view where oppression can operate throughout a system and act on different people within it. Russell and Malhotra (2002) reject the idea that simply “erasing” mistaken attitudes will permit equality to flourish.

This study recognises the need for clinicians and senior advocates for the STOMP agenda and *transforming care* to reflect on the words of Wolfensberger (1972):

“Many benevolent, humanistic clinicians seem themselves as a servant of the public, offering their services in a non-controlling fashion, they see their clients as free agents... their self-concept- in part due to the indoctrination received during training – is frequently incompatible with action perceived as controlling... here is where many human service workers deceive themselves, because their roles are not only almost always state sanctioned, but in an endless array of encounters between the server and served, the server is the interpreter of an agent for the intents of society, and wields a truly amazing amount of power and control, even if he may not consciously perceive himself doing so.” (p. 1).

4.3 Critical review of research

4.3.1 Medicine as the only power?

I am aware that clinical psychologists, whilst historically holding less power than medicine within clinical teams, are trained (uniquely) to doctorate level, a qualification that society values greatly, and with it an assumed level of “ability”. I found myself throughout this process wondering where clinical psychology undervalues the role of support workers and maintains ableism within the system. Clinical psychologists often take a lead role in the development of PBS

plans from functional assessment, and the supervision/training of staff (BILD, 2016). It will be therefore be the clinical psychologist who has the final say on a function of behaviour and agreed intervention, much like a psychiatrist does for medication. Clinical psychologists also hold a powerful remit in eligibility assessment; where ID service provision is strongly weighted on the base of a cognitive assessment solely under a clinical psychologist's control. Whilst I call for a "giving away" of psychiatry decision making on medication, how would clinical psychology as a profession respond to call for support workers to have more of a say over eligibility for learning disability services given many support workers thousands of hours working directly with people with this diagnosis? Whilst this study has cast a focus on experiences around medication, I must reflect on clinical psychology's power, where we are not as proficient at "giving away" psychology as we could be, in fact, we would do well to understand how we use our power to reduce "disabling" experiences for support workers and the people they care for.

4.3.2 Scrutinising research aim

4.3.2.1 Research aim: To gain greater insights into the practice of psychotropic medication in ID services and seek the participation of support workers, as a particular group of interest, in order to understand the medicating of people with ID from their perspective.

4.3.2.2 Gaining greater insight: This study analysed the data from interviews with support workers caring for people with ID who take psychotropic medication. The model constructed in this study has conceptualised an understanding of medication practice in ID services from the experiences of support workers, which currently has little research or models that can account for this specific topic. The method of GT used in this study sought to develop a model to explain the relatively unstructured data gathered; this method is in-fitting with a pragmatist epistemological position (Charmaz, 2017). On the basis of pragmatic pluralism and valuing knowledge based on utility for social action, it could be understood how alternative methods may hold utility in producing knowledge of different uses. The concepts constructed in this model could be further explored through quantitative methods, which could aim to find utility in

developing a measure of “disability” within ID service support staff based on the model constructed and using this to foster changes within services.

4.3.2.3 Participant demographics: This study interviewed eight people who work in a support role for people with ID who take psychotropic medication. Support workers were understood to be a diverse group, working in services that provided care for people with varying levels of need and in different settings. Support workers were therefore interviewed from specialist outreach, day services and supported living settings. The number of individuals interviewed were aimed to be around nine participants to adequately explore the experiences of support workers in their varying contexts. Due to technical error in recording, one interview was not possible to transcribe, leaving eight participants, whose data was used to construct the analysis.

It is of interest how the demographic make-up of the individuals interviewed for this study does not reflect the demographics of the wider care workforce. Whilst generalisability of this study’s analysis was not an expected outcome, it is of importance to explore why participants were not representative. Firstly, recruitment of participants was not straightforward and required multiple contacts with services, this meant a certain amount of opportunism was needed to be taken when potential participants came forward. Using a larger sample size may have provided opportunities for greater explorations of categories. Making connections with care providers was the main source of recruitment, which yielded little interest from participants.

The specialist outreach service had support workers who had frequent contact with health and social care professionals as well as requiring more experience for the role. It may be that this greater contact with professionals and slight distance from medication meant they were less hesitant to be interviewed by a research psychologist. Support workers from this service are largely White-British/European, they made up the largest group within the sample. The day and supported living services were much more ethnically diverse yet contributed a smaller number of support workers per service to the sample. It can be seen therefore how ethnicity is intersected with the professional development of a support worker and the subsequent access or desire to be a participant in

research. In future research, partnership and direct recruitment may increase the uptake of support workers willing to be interviewed.

4.3.2.4 Focus on medication: Medication was of specific focus within the aim of this study to explore the experiences of support workers. Support workers were keen to speak about these experiences and how they related to issues both with their senior colleagues and the people they support. The model has broader connotations for multiple abuses of power that can operate within an ID system such as restraint, or control over a person's affairs. It may have been prudent to develop the interview schedule to include questions around this. It is not however, the intention of this research to provide a broad explanation of support worker experience and therefore a more focused approach allowed for greater richness of interview data and clarity of the model. It may instead be of use to build on the model constructed in this study and carry out further research exploring other areas where power is impressed, by and on support workers.

4.3.3 Evaluating the grounded theory method

This study used a constructivist GT method from a pragmatist epistemological position. Epistemological position is a key element of evaluating qualitative research as it provides a framework for which to discuss issues beyond the gathering, analysis and reporting of words (Henwood & Pidgeon, 1992).

The method will be scrutinised using (Henwood & Pidgeon, 1992) criteria, this has been highlighted as an effective tool for evaluating qualitative research in psychology (Willig, 2013) on 5 key areas; 1) sensitivity to context, 2) commitment and rigour, 3) transparency and coherence, 4) impact and importance, and 5) researcher reflexivity. Whilst understanding that there are no criteria that can guarantee the "accuracy" (Henwood & Pidgeon, 1992) of research, the above criteria however represents good practice in the evaluation of qualitative research that broadly chimes with other guidance (Yardley, 2017).

4.3.3.1 Sensitivity to context: Contextual effects can be theorised in qualitative research; it is therefore important to remain sensitive to context by being aware of the perspectives of participants, the setting they are in, and the socio-cultural

context of the research (Yardley, 2017). Theoretical decision making must be evidenced to clearly demonstrate where the analytic categories and model have been grounded in the data (Yardley, 2000). Through line by line coding I ensured that small units of data were analysed at a time, resisting the urge to interpret large passages of data (see Appendix 8) and impose the researchers own precedence onto it. Only following this level of coding did focused coding and categorising ensue (see Appendix 10). In addition to this, I accounted for where the data contradicted codes or categories (see negative case analysis, Appendix 12).

Both in (Yardley, 2000) guidance and Henwood & Pidgeon's (1992) review of GT evaluation, the acknowledgment of the socio-cultural context and how this impacts on the data is crucial to effective understanding of the meaning constructed from the research. With regards to this study, I was aware that all support workers worked within an inner London borough; feelings of “ablement” and “disablement” may be a reflection of the context working in a city with very high costs of living in a role that is known to pay little. Equally the people they support are also likely to be affected by expensive cost of living and limited housing; further research may want to understand the experiences of support workers outside of this context.

Although not looking to reify generalisability, it is of note that despite many care workers, especially in London, being of BAME backgrounds (SfC, 2017), the accounts in this study were largely White and British. Further research may seek to gain the views of support workers from BAME backgrounds and their unique context or indeed explore if participant recruitment is itself racialised.

4.3.3.2 Commitment and rigour: The commitment and rigour of research is demonstrated through an in-depth engagement with the topic, showing appropriate aptitude in carrying out the qualitative research methods and thorough analysis of the data (Yardley, 2000, 2017). During this process I noticed I noticed how there was not always an ‘intuitive’ choice when it came to category formulation, where I had to gather a broader idea of what was being conveyed in the passage and why it would most likely to be one category rather than a similar one. Through using a constant comparison approach and memo writing (see Appendix 7 & 9) I ensured rigor in that initial codes and subsequent

focused codes/categories reflected the data from which they were constructed and allowed for full immersion into the data (Charmaz, 2014). Forshaw (2007) critiques the use of rigour and commitment in qualitative research evaluation due to the multitude of interpretations that can be seen as equally valid. Conducting this research from a pragmatist approach, rather than a radical relativist position, I accept the pluralism of knowledge yet consider rigour and commitment as a method of determining utility in how knowledge can be used for social action. Completeness of the data ensures a well-rounded understanding of the research topic. This was supported by “triangulation” (Charmaz, 2014), in which support workers were sought across different ID services with different relationships and proximity to professional teams.

4.3.3.3 Transparency and coherence: These evaluation terms relate to how clear and cogent the argument within the analysis is (Yardley, 2000). The persuasiveness of this research will be explored with participants who wish to comment on the coherence of the model and its explanation. Due to time restrictions, this has not been possible to date, but will be actioned going forward. The findings of this research were also shared within a discussion group at a challenging behaviour conference, broad categories were discussed with a group of peers to relate to that of the workshop facilitator’s own research in process (Sheehan, 2019), which is studying the experiences of involvement in psychotropic decisions for paid and unpaid carers of people with ID. Transparency ensures that there is an openness to the theorising and reflections of the researcher and the actions resulting from it (Yardley, 2017). During this process, I made reflexive memos about how my own personal assumptions may be influencing my thinking around the data analysis (see section 4.4 and Appendix 13) as recommended when carrying out constructivist GT (Charmaz, 2014). A reflexive account is also presented in this report (see section 4.4), which brings together my thinking from the memo writing process.

4.3.3.4 Impact and importance: Key to pragmatic epistemology in research is the generation of knowledge that is useful. Importance can relate to the generation of novel hypotheses or in challenging existing belief systems (Yardley, 2000, 2017). This research has shown its potential impact in raising the unique conceptualisation of how support workers experience “ablement”

and “disablement” in their psychotropic medication role. These novel insights add to a group that is currently under researched and has played little role in the development of new theory within the field of ID.

In practical and clinical terms, the findings and conclusions from this research and its conceptualising within the constructed model will be shared with the participants and the services they were recruited from. Broader dissemination has already occurred through the Challenging Behaviour- National Steering group conference, where its impact could be felt in different ID services across the country. The intention of the researcher is to gain dissemination through formal publication in relevant academic journals.

4.4 Reflexive account

4.4.1 The non-neutral researcher

Over the research process I have reflected on the impact of my interests and ideas on theory development; I have been a support worker myself and experienced the low wages, long hours and low levels of support that I see in current support worker roles. In contrast to the assumption of traditional GT methods (Glaser & Strauss, 2000), I cannot enter this research without being laden in prior assumptions, which will inevitably influence the questions I ask and the answers I received. I reflected on how my own prejudices about the power and influence of professionals over support workers is reflected in the number of categories that were used to construct the feelings of “disablement” compared to feelings of “ablement”. I decided to let participants know of my work background, which included my support worker role. I felt this had the effect of allowing support workers to speak more candidly with me, given the sense of shared experience. Despite this, there are trade-offs with this approach, as I am no longer a support worker. This may instead have given an impression of moving “up” from this role and making the power imbalance between the researcher and participant salient anyway. Given the model constructed in this study around “dis/ability” within the hierarchy of services, I am aware how this would be played out within the room during the interviews and limitations of my attempts to place myself in a “one down” position.

I also reflect on the many preconceptions or taken for granted knowledge about what it “is like” as a support worker. My sense of solidarity and desire to do the best for support workers yet my current role as a psychologist may have orientated me towards wanting a more uniform conceptualising that can lead to a fix of some kinds, the complex nature of relationships I wonder, was not something I had prepared for, as it is not something that is readily met with a solution.

4.4.2 The non-neutral research

Starting the research process without a strong theory to lead the study, I struggled with the inevitable problem for qualitative researchers of trying to make sense of levels of unstructured data I had never come across before (Henwood & Pidgeon, 1992).

The model has always felt difficult to grasp, from my original focus of the study to set out to understand the process of medication reduction. Relatively early on in the study, I found that STOMP was not as implemented as I originally thought, where my preconceptions led me to believe that various support workers were supporting people with ID to reduce their psychotropic medication and the study would be to understand how this process play out.

My first major learning opportunity was following my assumptions about processes occurring in the data; many of the participants were unclear on their experiences of supporting a reduction in medication despite this being a requirement of the participants to be interviewed. I found myself becoming desperate within the interviews to stick to the details of the process I had sought to understand whilst at the same time being aware of allowing the support workers to tell their story. It became evident to me that support workers did not want to talk about the start to finish process from A to B where a medication was reduced, and they experienced certain things and acted in certain ways, that would glean insight into how this process could be made more efficient. I realised how much of my own assumptions I had brought into this study and where I wanted the data to go, it was not going how I expected.

I came to accept that support workers were less interested in the specifics of reductions, for them I saw that their whole role around medication was fraught with difficulties, anxieties and disagreements and that this was largely directed towards those they felt to be in charge of psychotropic medication such as the managers of the care provider that they worked for or the healthcare professionals in the CIDT. There was a sense of a double-bind, where they are responsible for administering psychotropic medication, yet have very little say over how this psychotropic medication is delivered or whether it is even prescribed or not. There was also the impact that this had on the people with ID whom they supported, in general, support workers told me how they recognised this group as being vulnerable, the impact that medication has on them and how their direct support of high frequency interactions (compared to their managers and professionals) puts them in an important advocacy role, yet one that holds little power.

Less obvious to me was a separate point of reflection, the idea of process. I was still seeing the experiences told to me from the interviews as simple form of process, which can be tracked from a start to finish, albeit in the broader sense of medication rather than over medication or reductions in medications. Yet, my oversight became clear where the language of a linear process was struggling to explain the interactions I was witnessing unfold in my interviews or the categories I had constructed from the data. It was in this moment that I realised how the focus on a linear process had distracted me from what was happening for support workers in the data, something far more pertinent yet far less procedural, they were telling me about relationships.

4.5 Conclusion

This study suggests that support workers experience complex and dynamic relationships with other actors within the ID system. From the analysis it has been concluded that these relationships negotiate positions of “dis/ability” as experienced by support workers caring for individuals who take psychotropic medication. The concept of “ableism” operating within a system and experiences in this way is not known to have been conceptualised until this point. By increasing the scope of associated discrimination to support workers,

there can be greater insight into understanding how structural inequalities within ID services affects those within it. This study has demonstrated how ableism against support workers can impact on the further “disablement” of people with ID.

The experiences of disability and ability in different relationships within the system offers clear directions for clinical psychologists to support the better delivery of services for people with ID. Clinical psychologists often occupy a unique role within ID services that recognises and intervenes at multiple levels of context around and including the identified patient. This model provides a systemic framework for working to challenge the “disablement” of support staff and create a more enabling environment for which people with ID would benefit. To overcome the impact of organisational culture and “disabling” processes, professionals need to collaborate with support workers (Haines, Wright, & Comerasamy, 2018; Haydon-Laurelut, 2011).

Further research would look into how support workers are “disabled” by the system that they work within, which moves beyond the specific role around psychotropic medication that this study focused on in order to develop ID services that are more egalitarian and ultimately providing a better service for those that use them.

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6. APPENDICIES

Appendix 1: University of East London ethical approval

SCHOOL OF PSYCHOLOGY RESEARCH ETHICS COMMITTEE

NOTICE OF ETHICS REVIEW DECISION

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Matthew Jones-Chesters

SUPERVISOR: Dora Whittuck / Poul Rohleder

STUDENT: Dominic Wrein

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: TBC

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments

have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

- 3. NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

APPROVED

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐

HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐

MEDIUM (Please approve but with appropriate recommendations)

☒

LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer (*Typed name to act as signature*): M H Jones Chesters

Date: 15 June 2016

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix 2: Advert to recruit participants

RESEARCH PARTICIPANTS WANTED

SUPPORT WORKER VIEWS ESSENTIAL

Would you like to take part in a study where your experiences are crucial to the research outcomes?

I am looking to understand the experiences of support workers caring for people with a learning disability who take psychiatric medication. I am interested to know about your experiences of supporting someone to reduce their psychiatric medication.

This research is being carried out as part of a doctoral thesis at the University of East London.

You have the opportunity to speak anonymously about your experience. Your views may have an influence on shaping services for people with learning disabilities.

Please contact me on the email below for a full participant information sheet including consent, anonymity and further information on the study aims.

Many thanks:

Dominic Wrein
Trainee Clinical Psychologist
University of East London

u1622905@uel.ac.uk

INFORMATION SHEET FOR PARTICIPANTS

University of East London

Principle researcher: Dominic Wrein - Contact details: u1622905@uel.ac.uk

Supervising researcher: Dr Dora Whittuck - Contact details: dwhittuck@xxxxx

Research information

This information is to provide you with the necessary details when considering whether or not to participate in the research study. This research is being conducted as part of a Professional Doctorate in Clinical Psychology at the University of East London.

Title of research:

What processes are involved in supporting individuals with an intellectual disability to reduce their psychotropic medication usage?

What is the research about?

The research aims to develop a model that can help to understand how care workers are able to support people with intellectual disabilities to withdraw from psychotropic medication. When completed, this research be written up as doctoral thesis. The research findings may also be used to write future articles for publication in academic journals or other suitable mediums for dissemination.

This research requires participants to be interviewed who are currently working as a care worker (or equivalents e.g. support worker) for people with intellectual disabilities in a supported living or residential home. Participants must also have recent experience in or are currently supporting a person with intellectual disabilities to reduce their psychotropic medication (in this case, medication

prescribed for behaviour perceived as challenging). Whilst questions may vary depending on the responses from participants, it can be expected that you will be asked questions such as “Why do you think it is important to reduce psychotropic medication in people with intellectual disabilities?”, “What do you think about reducing the medication of the person you support?”, “How involved were you in making decisions about whether the person you support should reduce their medication”

The research does not involve any risk to the participants taking part, it may be that the interview questions and the topics they explore will make you upset. Should this be the case, the researcher can discuss with you the details of services that offer support.

The interviews will likely be conducted either at your place of work or at the local community learning disability team. Other methods of interviewing are also available were needed e.g. online video streaming.

Anonymity of your information

Each participant will be individually interviewed by the principle researcher. The interview will be recorded using an audio recorder for the sole purpose of transcribing the interview questions and answers. Transcriptions will be anonymised, meaning that your name will be replaced with a pseudonym to protect your identity. The principle researcher will be the only person who has access to and listens to the audio recordings. The anonymised transcript may be read by the supervising researcher or the examiners who assess the research as a thesis.

Storage of the audio data and transcriptions will be kept in separate digital files, encrypted and saved with a password. The audio data will be deleted once examinations have been completed and the anonymous transcripts will be kept for a further 3 years in case of use in future research articles.

Within the write up of the study, there will be a small number of direct quotes from the anonymous transcripts, which may include comments made by yourself during the interview, although quoted using a pseudonym. Whilst every

effort is made to protect your identity, the study write-up will be publicly available and in rare occasions someone close to you may be able to deduce something that sounds like it has been said by you.

You are in no way obligated to take part in this research study and are free to withdraw at any time with no consequence for doing so, you do not have to give a reason for withdrawing. Due to the specific nature of the research, each interview influences the subsequent interview taking place and so themes emerging from your interview will impact on the direction of the next one. This will happen even if you withdraw from the study. Should this happen, every effort will be made to ensure that justifications discussed in the write-up of this research are kept general and without using quotes from your interview.

If you have any questions, please do not hesitate to ask me. Should you wish to take part in this research study, continue on to the consent form below. Please ensure that you read it thoroughly and understand what it explains, when ready please sign and date the consent form.

Thank you for taking to the time to read this information sheet

Yours sincerely,

Dominic Wrein

Trainee Clinical Psychologist

Please note: Should you have any concerns about the nature of this study or the way in which it has been conducted, you can contact the supervising researcher (details above) or the Chair of the School of Psychology Research Ethics Sub-committee: Dr Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ (Tel: 020 8223 4493 Email: m.finn@uel.ac.uk)

Appendix 4: Consent form for participants



CONSENT FORM FOR PARTICIPANTS

University of East London

Principle researcher: Dominic Wrein - Contact details: u1622905@uel.ac.uk

Supervising researcher: Dr Dora Whittuck - Contact details: dwhittuck@xxxxx

Consent to participate in a research study

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will be strictly anonymous. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw after analysis of data has begun, it will not be possible to remove my anonymous data from the study.

Participant's Name

Participant's Signature

Date:

Researcher's Name

Researcher's Signature

Date:

Appendix 5: Interview Schedule

INTERVIEW SCHEDULES

Interviews will follow a semi-structured approach; questions will not necessarily be asked in any particular order represents a complete or exhaustive list of questions. The schedule provides a framework to be covered. The following structure has been based on guidance for Grounded Theory data gathering as outlined by Charmaz (2006) using open-ended, immediate and ending questions.

Introduce participant

Discuss consent, anonymity and right to withdrawal. Build rapport with some basic ice-breaker questions and housekeeping information (e.g. fire safety)

Questions

Open-ended

1. Tell me how you came to be a care worker for people with intellectual disability?
2. What was your first experience of administering (psychotropic) medication?

Immediate

3. What, if anything, do you know about the psychotropic medication for the person/people you support?
4. Why do you think it is important to reduce psychotropic medication in people with intellectual disabilities?
5. What do you think about reducing the psychotropic medication of the person/people you support?
6. How involved were you in making decisions about whether the person you support should reduce their psychotropic medication?
7. How have these experiences affected the relationship you have with the people you support?
8. What helps you manage any difficulties as a result of the reduction in psychotropic medication?

Ending questions

9. Tell me how your views may have changed since you first supported a person with intellectual disability to reduce their psychotropic medication?
10. After having these experiences, what advice would you give to someone who has just begun supporting a person with intellectual disability to reduce their psychotropic medication?
11. Is there anything you think I should know to understand what it's like supporting someone with intellectual disability to reduce their psychotropic medication?

Debrief

How has it been having a conversation with me?

Is there anything you would like me to leave out?

Do you have any questions for me about the interview or research more generally?

Appendix 6: Example of theoretical sampling

Except from memo following interview 4:

Distance from CIDT and salience of power

Closeness to the community intellectual disability team has consistently been mentioned as incredibly important across the past four interviews, this team is in a privileged position in its proximity to the CIDT. I wonder what is being communicated through this in either geographical or relational closeness to a powerful source?

P3 used the term "team upstairs", despite not actually being upstairs appears to encapsulate this to me. It made me think what/how this experience is different in services without such close contact or "first name basis" as P1 put it.

In these first four interviews, there were clear difficulties with this power dynamic; on one hand the utility and feeling of privilege was clear in being close to the CIDT but also feeling underutilised or devalued by the same team it makes me think of the difficulties of family relationships and wanting to be contained by an authority figure but the pain in not feeling recognised by it.

Sampling & question plan: I question how this is experienced by more distant services; do they see the CIDT in the same way? How does it affect their relationship? – further sampling should recruit support workers from different services e.g. supported living or day services, which are not within the same building as the current service. The formal addition of questions should be made to the interview schedule that asks about this distance to the CIDT team to fill gaps in the data.

1. How much support do you receive from the community intellectual disabilities team?
2. Have you ever met anyone from this team?
3. What would you say your relationships is like with this team?

Appendix 7: Excerpt from memo following raising of initial codes to focused codes

Linking role satisfaction with agency

When coding P7's interview, I came across her difficult introduction to challenging behaviour, that was not uncommon for many of the people I interviewed, where this often felt like being thrown into the deep end with little training or prior expectation of what this would be like.

I was struck by the feelings of being overwhelmed that had permeated across my participants; when comparing P7's recollection of this compared to P5's, the development of this experience is stark. Both talk of feeling overwhelmed and not used to the behaviour they are witnessing and experiencing. With P7, there was a sense of curiosity to understand what had happened and a feeling of being able to address this, whilst with P5 there was sense of nihilism, where neither him nor the person with intellectual disability could change in a positive direction with regards to their behaviour. In this case, P5 spoke much more of the behavioural changing effects of medication to calm the residents down, whilst P7 spoke emphatically about the need to try alternative strategies first. I feel this mainly came from her experience of strategies working previously and them being taken on by the organisation, whilst P5 spoke of isolation and a split staff team. The following consequence of this, was someone who found a lot of enjoyment in their role and puts this down to the successes in addressing challenging behaviour, where P5 spoke of no-job satisfaction, based on his experiences and perception of the little progress for the people he supports and lack of support from his organisation.

This feels like the opening up of a process or theory when supporting people with intellectual disability on psychotropic medication, the feeling of being introduced to challenging behaviour and the subsequent conceptualisation of this experience; feeling empowered to support that person to improve or maintain wellbeing, this opens a question in my mind about medication due to the personal experience of successful alternative interventions and therefore feeling agency to support someone independent of psychiatric overview.

Appendix 8: Examples of initial coding showing the line-by-line approach and focussed coding that follows

Participant: P3

Dominic	And so, it feels, I mean if that's not happening, it feels there's barriers of some kind to that happening, have you got a thought or an idea about what those barriers might be in your own experiences?		
P3	I think again the, there are- is a lack of consultation in- in er all- all of the parties involved, I think- I think that has to happen to get you know clearer ideas or a picture of you know of what's going on, you know erm I think erm- again said it already but maybe they- the thing that we aren't worthy of that information or we aren't trained in that so why- so why will- so why would they- would they ask us or consult us. Erm, yeah	<i>Experiencing lack of consultation across MDT; conveying importance of listening to all stakeholders; conveying power imbalance; conveying professionals' attitudes to support workers</i>	<u><i>Being excluded from medication decision making</i></u>
Dominic	Yeah. I suppose we have talked a little bit about erm challenges around medication changes, erm do you have erm, any thoughts about why reducing medication is kind of important in general or as we know there is the kind of STOMP agenda around at the moment that I know you're familiar with, what's you kind of thought about the whole reducing medication kind of process that's kind of happening a bit at the moment?		
P3	Well, erm I think I think erm you know it's- it's- it's often used- it's	<i>Criticising medication as a form of restraint;</i>	

	<p>often used as- as- you know restraint I think- and I think it's- it's important to highlight when that's happening and to come up with other ways you know supporting you know individuals, I think so- I think- I think it's- there has become a culture of giving out- of giving out you know these meds when- when actually you know other you know ways haven't- haven't- haven't- been looked at you know first of all and I think- and I think- so I think- I think you know it's a great thing, and I think there are individuals out there who need to be on these meds and- and it's very important for those er but there are also a lot of other people who- who could do with coming off and they- they would may well enjoy and get a lot more out of life, off the medications.</p>	<p><i>conveying importance of being aware of overmedicating; Conveying structural issues around overmedication; Criticising medication as a first line of intervention; Clarifying medication utility in some individuals; criticising side-effects of long-term medication usage</i></p>	<p><u>Overmedication as inherent in the structure of services</u></p>
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Participant P6:

Dominic	Yeah, and erm how did you manage to kind of get through that period?		
P6	Well, there was er, basically with experience with time, talking to my partner; asking him because he works also with quite difficult group, and from him and reading really. I have a very good er mum of this guy who I was looking after, she had a big library because she was very into physiotherapy and this mum and dad, so I read, and asking her, asking people, asking my old mate, reading.	<p>Coping through experience; reaching out to partner; Doing own reading; Utilising resources of client's parents; Asking others for support</p>	<p><u>Drawing on own resources to learn about medication</u></p>

Dominic	Yeah, so doing quite a lot of your own work		
P6	A lot- a lot	Doing a lot of own work	
Dominic	So almost, training yourself up		
P6	I had to, I had to, because I don't think they- I actually I don't think many organisations have the right training	Having to train self-up; not feeling training was right	
Dominic	Yeah- yeah, what do you think- what do you think's happening there? Er. Why? [laugh]		
P6	[pause]		
Dominic	Why do you think, it seems like a bit a theme that people often do their own reading, their own work, erm yeah? [laugh]		
P6	I think, that there is [pause] lack of vision, er lack of well-trained managers, the management is very poor, the changes in social services are very drastic and they thinking you know about money in the short term that they are not thinking about consequences in the long term. I also think that families are not always well supported, kind of in a level of information, a level of education for them to really deal with their family and relatives [pause]. I think managers need to be better trained really, I think- there is- there is need for more sense of humanity, more sense of compassion around our clients [pause] the orientation at the moment seems to be quite a lot about we do this we very good at	<p>Conveying management as visionless; not feeling training is adequate; changing social care; critiquing budgetary short-termism; criticising family support (education)</p> <p>Thinking manager training is insufficient; Conveying loss of person-centred work; feeling too many targets; Feeling focus neglects clients (needs?)</p>	<p><u>Criticising management of the service</u></p> <p><u>Conveying service as moving away from the person</u></p>

	this, we tick boxes and we sure. yep. And the grounds where we are working with our clients, with our customers sometimes are neglected so I think the management structure is not right [laugh]		
Dominic	Yeah, yeah, yeah. So, it a kind of a difficulties that are higher-		
P6	It's too hierarchical, there's no many managers and too few people on the ground, and a lot of money there and where's the money here, yeah?	Conveying top heavy organisation structure; critiquing focus on money	
Dominic	Mmm- mmm. So, how do you think that erm impacts on the services-		
P6	Ah a lot, it impacts a lot because if- if there is no vision from the management, there is no [pause] focus or quality of the service that more focus on showing things, ticking boxes, targets. Me, how can you measure that a person is healed, or her health/mental health is better ticking a box, it isn't yeah? So, I think, quality is very difficult to measure, and it only- it's only seen with the long term, it's not just because he's doing this today great or tomorrow. I think it's a process, a process is very difficult to quantify yeah, so I think actually it's the mental structure that we need to change a focus and it's about quality and it's about- we- we how do you speak about love in our service, and compassion and I think it's about love and compassion. Simple.	Feeling lack of vision impairs quality of service; Criticising target agenda; Questioning outcome effectiveness of services; Critiquing measurement of quality; Conveying difficulty in quantifying process; Feeling need to change organisational attitude (kinder?)	<u>Criticising value base of the organisation</u>
Dominic	Why? Why do you think erm love isn't mentioned enough?		

P6	<p>There is a power on that, we- we don't understand what love is [laugh] Isn't that, it isn't about men-men and women loving each other, I think love is- it's tougher than that, it's about how we relate to each other it's about kindness really, it's about do good and I'm following your principles time and erm, and being empathetic isn't it and putting yourself, I mean how you feel, having schizophrenia for example [pause] yeah, putting yourself there, or hearing voices, how would you feel then? But no, they- it's a lot about suppressing- suppressing and there is not enough room for when we are so boxed and targets, there is not enough room to explore all quality of things, and interactions and relationships and-</p>	<p>Feeling love is misunderstood; Redefining love</p> <p>Conveying ideals of love to organisation and PwLD;</p> <p>Trying to understand experience of PwMH Feeling that targets suppress relationships forming</p>	<p><u>Believing organisation is threatened by emotions</u></p>
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Appendix 9: Excerpt from memo during the construction of categories

Glass ceiling and prejudice towards support roles:

Whilst categorising the focused codes, I've been asking myself the question what is it about the professionals that makes them so desirable? Why is their input appreciated so much, why are they seen as so unquestionably valuable in their support, with few downsides other than wanting more input? From the interviews and constructed categories, criticism was largely focused towards wanting more connection, more of a say into their decision making and to feel valued by them. Why? I feel it's this impression of expertise, how entrenched the idea of needing a qualified or certified role is the only way to hold expertise and even if this is referred to, there is a 'right type' of expertise and therefore the support workers are devalued by not holding the approved form of it. The consequence therefore is to be looked over for decision making around medication, to have training needs ignored, which thus reinforces the support worker's dependence on those who are 'more trained'. Of interest is how one-sided the relationship appears to be between professionals and support workers; I was able to interview support workers from a variety of services with a varying degree of connection to the CIDT and service specialism. For those closest to the CIDT, this was seen as an unanimously positive thing, being closer to the expertise and maybe borrowing this power from them where possible. Problems came when the respect was expected to have a mutual element to it, where power could be shared a little more. From these support workers, there were skills of being a specialist outreach service that potentially 'grades' support workers? The experience however does not fit the expectation, from these participants, it felt that they were defined by their support worker role/title, one could be the most experienced, skilled support worker there is, but a support worker they still are. So how is this related to medication? Medication is seen as requiring the most amount of expertise and training to speak to, where prescribing is the sole privilege of the medical practitioner. Whilst there has been movement in recent years, clinical teams are still largely led by medics, in this case a consultant psychiatrist. It therefore makes sense that an unqualified staff group have least say and connection to the intervention that requires one of the most qualification.

Categories appear to coalesce around the main relationships that support workers have within the intellectual disability system

Feeling a part of the MDT	Facing exclusion from decisions
Being accessible to CLDT	Being disconnected to medication
Access for agency	Being excluded from medication decision making
Being supported through close links to CLDT	Being excluded from medication decision making
Building meaningful relationships with CLDT	Being excluded from medication decision making
Communicating concerns to higher powers	Being left out of medication decision making
Conveying access with reducing power imbalance	Being separate to medication decisions
Conveying benefit of being relevant to the CLDT	Competing interests in excluding some stakeholders
Conveying importance CLDT access for ensuring best practice	Conveying exclusivity of medication knowledge
Conveying importance of working with CLDT	Conveying imparity of information sharing
Depending on CLDT	Excluded from medication decision making
Diffusing conflict through CLDT	Exclusion from medication decision making
Feeling contained by close CLDT access	Feeling greater disconnect to professionals
Being contained by structure of organisation	Having some distance from medication administration
Appreciating support from colleagues	Limited involvement in medication
Feeling contained by higher support structures	Medication issues as inaccessible to non-professionals
Feeling contained by local, familiar CLDT	Accessing CLDT differs across support worker roles
Feeling supported by CLDT	Conflicting relationship with CLDT
Feeling supported compared to other LD service	Disparity in resources between stakeholders
Feeling supported through access to the wider team (CLDT)	Feeling disempowered to challenge medical authority
Gaining support from CLDT	Identifying competing roles between stakeholders
Reaching out to professionals	Being uncertain around justification of medication usage
Seeking connections to the CLDT	Being uncertain of agency / exercising own power
Seeking support from colleagues and CLDT	Conceptual difference between stakeholders
Valuing contact with CLDT	Juxtaposition of access and exclusion to CLDT
Conveying practicalities of medication	Lacking access to intellectual disability teams
Being critical of medication	Lacking agency to challenge medical professionals
Associating medication with abuse of power	Lacking agency to challenge medication decision making
Challenging medical authority	Lacking trust / confidence in professionals
Challenging pre-eminence of medical intervention	Lacking trust in medical management of PwLD
Conveying medication as a form of restraint	Overlooking needs of PwLD
Conveying medication as one factor in wider issues for the support worker role	Lacking power as a support worker
Conveying power struggles between models of care	Recognition of service disparity across different LD settings
Conveying powerful interests in medicating PwLD	Struggling with duality of role (levels of support worker)
Conveying vested interests in medicating PwLD	Lacking medication communication
Critiquing medical approach to challenging behaviour	Being critical of communication of medication reduction
Critiquing medical approach to challenging behaviour	Breaking down of communication within system
Dehumanising aspects of medication	Having communication challenges with parents of PwLD
Dehumanising of PwLD by medical professionals	Lack of medication communication
Expecting medication as part of broader approach	Lacking communication around medication
Regarding medication as dehumanising PwLD	Lacking communication around medication changes
Feeling uncertain about medication as a core intervention	Lacking medication communication
Holding professionals responsible for giving medication information	Prioritising communication with CLDT
Lacking person centred approach/institutionalised	Feeling devalued
Medication replacing emotional support	Being undervalued as a role
Overmedication as inherent in the structure of services	Being undervalued as a support worker
Questioning medication explanation of challenging behaviour	Feeling support worker skill set is underappreciated
Questioning medication as a sole option	Feeling undervalued as a role
Questioning primacy of medication as an intervention	Overworking of support workers
Questioning the medical model	Professionals lacking appreciation for pressures on support workers
Regarding medication as dehumanising PwLD	Scapegoating support workers
	Undervaluing of support workers

Being uncertain about complexity	Deferring to psychiatry
Being uncertain about effects of medication change	Expecting medical profession to resolve difficulties with PwLD
Being uncertain of changes from reduction	Expecting medical professionals to resolve difficulties
Being unsure about how to manage challenging behaviour	Feeling subservient to psychiatrist
Contradictory medication practice	Feeling uncertain about worthiness of medication training
Doubting medication knowledge / experience	Not seeing role in decision making around medication
Doubting own knowledge about / role in medication	Powerlessness to address side-effects
Doubting role in medication choices	Role in identifying and communicating health needs of PwLD
Experiencing uncertainty around medication-behaviour interactions	Seeking to understand medical point of view
Lacking confidence in medication administration	Subjugating own agency / power around medication
Lacking awareness of medication	Subjugating own role in medication
Medication knowledge lacking across support worker services	Unsure of access to medication decision making
Needing to feel confident in working with medication (reductions)	Deferring medication opinion to others
Feeling uncertain about competencies	Deferring medication responsibility to nurse
Feeling uncertain about efficacy of medication	Having medication presented as a solution
Feeling uncertain around medication side effects	Not wanting to take things further
Feeling uncertain of role within organisation	
Struggling to implement successful strategies of behaviour	Understanding alternatives to medication
Struggling to understand role in supporting PwLD	Increasing person centred practice
Struggling with lack of medication knowledge	Advocating for a holistic approach to challenging behaviour
Uncertain about medication effects	Alternative approaches to medication
Uncertainty about aspect of role	Conceptualising PwLD's difficulties behaviourally
Uncertainty around definition of abuse	Maintaining a client centred approach to medication administration
Feeling conflicted about benefits of medicating PwLD	Preferring a holistic approach to understanding/treating PwLD
Feeling conflicted about the use of medication in PwLD	Recognising psychological approaches to challenging behaviour
Being conflicted about medication reduction per se	Social, health and financial benefits of using alternatives to medication
Claiming ownership over medication role	Taking a holistic approach
Improving medication practice	Using psychological approaches to challenging behaviour
Conveying changes of practice over time	Using psychological approaches to facilitate medication reduction
Responding to medication issues	Using psychological approaches to facilitate medication reduction
Using experience in medication decision making	Using psychological approaches to facilitate medication reduction
Using medication sparingly	Using psychological approaches to facilitate medication reduction
Using medication sparingly	Wanting alternative approaches to medication
Working through medication changes with person with intellectual disability	Questioning western-centric view of medication
Conveying medication reduction as an individualised process	Matching LD work to values
Monitoring medication	Hoping for change
Reducing PRN medication usage	Conveying disparity between medication and non-medical approaches
Staking worth around medication decision making	Learning from different cultures
	Medicating PwLD as a western approach
	Wanting support from psychology to advocate for medication reduction

Relationship between support workers and: **Care provider management**

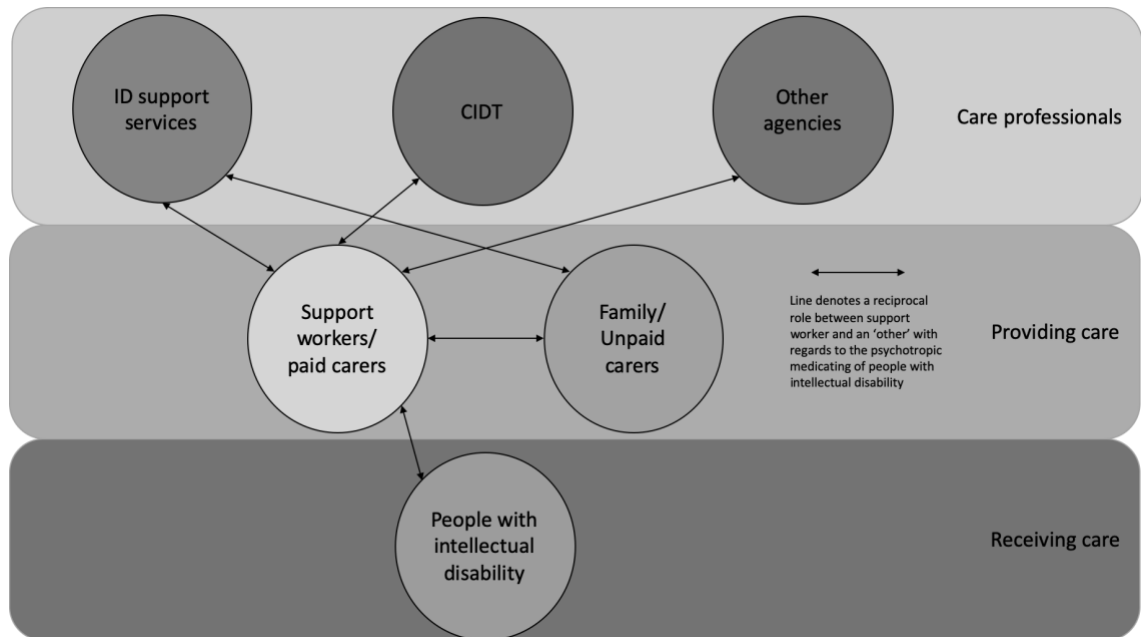
Shunning medication responsibilities Being given roles despite lack of confidence Being overwhelmed by medication expectations Conveying responsibility of medication administration Feeling responsible for PwLD's behaviour Feeling responsible within her job role Medication going against ethical position on administration Non-aligning of physical intervention with value base Responsibility of supporting PwLD on medication Being unprepared for medication responsibility Unprepared for medication responsibilities Unwanted responsibility for medication Having to manage challenging behaviours Justifying her decisions around medication Feeling trapped in medication role Feeling trapped within role	Feeling unprepared for complexity Being unprepared for challenging behaviour Being unprepared for challenging behaviour Being unprepared for challenging behaviour Being unprepared for medication change Being unprepared for medication changes Being unprepared for medication changes Being unprepared for role of medication Being unprepared for working with challenging behaviour Being unprepared to work with challenging behaviour Expecting community visits with PwLD to go badly Feeling underprepared for medication changes Feeling underprepared for medication changes Feeling unprepared for challenging behaviour Feeling unprepared for challenging behaviour Feeling unprepared for medication change Feeling unprepared for medication changes Feeling unprepared for medication changes Losing sense of control over work responsibilities Needing to be prepared for medication reduction Preparing for difficulties following medication change Preparing for effects of unannounced medication changes Preparing for working with PwLD Trying to prepare for the unknown Unprepared for challenging behaviour Having expectations about personality change following medication change
Lacking appropriate medication procedures Absence of STOMP Being unaware of reduction policies Being uncertain about appropriate medication administration Criticising method of medication reduction Criticising timing of medication reduction Curiosity about a formal reduction policy Curiosity about formal reduction policies Disagreeing with method of medication reduction Encouraging a culture of silence on errors Superficiality to current medication role Failure of safeguard in medication process Lacking coherent reduction plan Conveying poor medication practice Lacking structured medication plans Not experiencing medication change Overlooking impact of medication on PwLD Heavy handed approach to medication Relaying errors in medication procedure	Being resourceful Drawing on own resources in place of experience Drawing on own resources to learn about medication Externalising experience of behaviour Gaining agency through self-directed learning about medication Learning to work with limited resources Acting effectively whilst undervalued Seeking medication knowledge Seeking medication knowledge Seeking to understand challenging behaviour Self-directing medication learning Self-directing training Taking medication learning into own hands Unconventionally acquiring medication knowledge Using the resources available at the time Utilising resources available at the time
Lacking medication training Conveying training issues at all levels of staffing Educating support workers to improve agency on medication Expanding the support worker role in medication Feeling current training is not enough Feeling unable to pass on medication advice junior colleagues Feeling under trained Feeling under-qualified in medications Lacking formal medication training Medication training needs not being met Needing agency over medication Questioning training applicability Struggling with advice given Training is important Training not adequate Wanting to learn about medication Lacking parity in medical training Questioning induction process Questioning induction process Experiencing medication as a specific area of need	Having supportive from senior staff Finding support in staff Reaching out to colleagues during stressful experiences Reaching out to colleagues who could be trusted Sharing medication concerns with supervisors

Feeling empowered	Experiencing barriers to good practice
Feeling contained through medication procedure	Experiencing a culture of mistrust amongst staff
Feeling trusted to do role	Feeling frustrated with medication attitudes
Empowered to address health needs	Feeling scrutinised/judged about decision to medicate
Having a role in changing behaviour	Having a divided / confrontational staff team
Taking positive from first experiences	Conveying support workers as a broad church
Having a varied support worker role (fulfilling)	Conveying issues as entrenched in work culture
Changing procedures of medication administration	Conveying management as out of touch
Becoming accustomed to expectations	Lack of trust in medication role
Being more confident around medication	Lacking confidence in co-workers
Building medication skills and recognition within role	Loosing trust in protections of job role
Developing confidence / competence in working with PwLD	Oppressive nature of medication practice
Developing skills / confidence	Organisational disinterest in side-effects
Feeling more accustomed to complex needs	Needing containment
Finding meaning in the role	Uncertainty in working co-workers
Finding pleasure in a challenging role	Working in environments with poor practice
Habituating to work with people with intellectual disabilities	Conveying resistance to change of practice
Having control over medication process	Criticising management of the service
Having medication knowledge to have medication agency	Criticising value base of the organisation
Querying changes	Experiencing difficulties in partnership working
Reconstructing submissive role of support worker	Greater medicating over time
Rejecting medication responsibility	Unprepared for institutionalised practise
Resisting against exclusion from decision making	Differing views on structure of LD service
Resisting against medical authority	Experiencing poor medication practice
Resisting against medical authority	
Needing support workers to playing active role in medication management	Conveying medication as choice of underinformed/supported
Questioning long term medication usage	
Questioning medical professionals	Suspecting training as a means to protect professionals / management
Questioning quality of medication decision making	
Seeking clarity around role in medication	Needing to feel contained within the structure of the organisation
Seeking clarity around role in medication	Lacking support in medication skills / knowledge
Seeking clarity on role in medication reduction	Being under supported in medication role
Finding voice on meds as support worker	
Needing to resist unquestioning role	
Balancing resistance with lack of power	
Pushing personal boundaries	
Being aware of medication changes	
Being introduced to medication	
Early awareness of medication of PwLD	
Recognising medication as integral part of role	
Making peace with injustice	

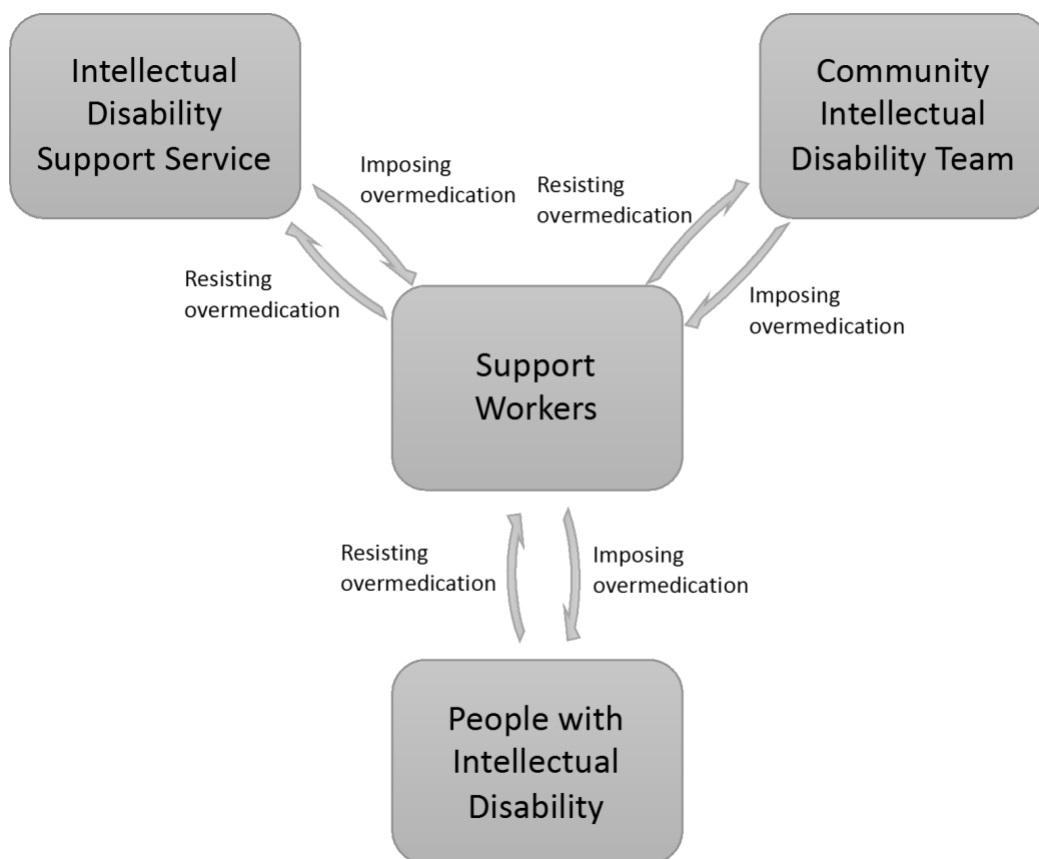
Relationship between support workers and: **People with intellectual disability**

Being a voice for people with intellectual disability Advocating for PwLD Advocating for PwLD as core role of support worker Conveying medical professional's lack of understanding of PwLD Empathising with PwLD Feeling challenging behaviour hinders advocacy role Lacking medication knowledge as a barrier to effective advocacy Need to advocate for PwLD PwLD's voice depending on support worker inclusion Successfully advocating for PwLD Successfully advocating for PwLD Wanting to have a voice for PwLD	Being uninvested in role Job instability Job instability Assessing career options Being open to work experiences Changing career Settling on working within intellectual disabilities Struggling to establish preferred career path Trying other things before care work Working across learning disability services Coming across LD work unintentionally Entering role through contacts Experiencing job insecurity Exploring work with PwLD Having a break from working in UK Having previous work before LD Holding different jobs in LD care sector Holding multiple care roles Holding short term roles Having a variety of LD roles Changing role Changing roles Having doubts about the future Having a less active role with supporting individuals Creating conflict with PwLD Having a difficult introduction to LD work Holding negative appraisals of PwLD Conveying low job satisfaction to the needs of the PwLD Lacking an understanding of the PwLDs needs Seeing PwLD's behaviour as nuisance Removing responsibility for role / support Removing responsibility for role / support Sceptical of PwLD's relationship forming Seeing supportive action as an additional task for staff Struggling to understand PwLD fast food interest Conveying PwLD as a risk to managed Implementing own (tougher) strategies
Witnessing impact of medication Being aware of impact of overmedication on PwLD Being certain of impact of medication change Being made aware of impact of overmedication Being made aware of medication criticism / over medication Conveying side effects of medication Critical of medication due to side effects Disruptive role of medication in day to day life of PwLD Equating unpreparedness with increased risk Experiencing medication as having significant consequences Experiencing medication as having significant consequences Highlighting complexities of medication reduction Highlighting risk of poor medication communication Highlighting safety risk from poor medication communication Highlighting safety risk from poor medication communication Impact of being undertrained on PwLD Conveying impact of medication reduction on individuals rights Leading from uncertainty to poorer care Negative impact of being uniformed Medication impacting on PwLD's quality of life Recognising adverse effects of medication Recognising individual impact of medication Struggling with role following medication change Conveying pressures of low staffing on supporting PwLD	Feeling hopeless Feeling hopeless about improving behaviour Feeling overwhelmed by challenging behaviour Feeling unable to prevent challenging behaviour Feeling uncertain about behaviour and interventions Interpreting behaviour following medication reduction Interpreting expression of side effects in PwLD Being disillusioned in ability to support current PwLD Lacking understanding of the person with intellectual disabilities Having low expectations of PwLD Having low expectations of PwLD (damage limitation) Conveying PwLD as having little to give Experiencing the PwLD's behaviour as burdensome Feeling burdened by PwLD's behaviour Finding complexities of client group a challenge
Relating to person with intellectual disability Re-establishing relationship following medication changes Re-evaluating relationship with person with intellectual disability Reconstructing role with PwLD Relationship as two way process Developing relationship with person with intellectual disability as self-evident Having different relationships with individuals with intellectual disability Having relationship as part of the role Connecting with PwLD Valuing contribution of PwLD to her role	
Recognising people with intellectual disability's vulnerability Conveying psychotropics as serving staff over PwLD Feeling complicit with poor medication practice Medicating lack of resources Institutions facilitating overmedication Feeling concerned about repercussions of inappropriate medication use PwLD being left out of medication processes PwLD having limited voice on their medication Seeing medication as effective for society at detriment of PwLD Seeing PwLD as a marginalised group Conveying service as moving away from the person Lack of agency in PwLD Lack of person centre medication planning Conveying stigma of mental distress	

Appendix 11: Development of the model, situational mapping



Five different actors were constructed from the analysis that relates to support workers, line are only connected between support workers and others due to the experiences of support workers being interviewed and their connection to others being honoured, it is predicted that other such reciprocal roles could be constructed should their direct experiences be heard. For the purpose of this analysis, it is the support workers connections that are of interest due to the research interest in the experiences of this group. Also of note, is that whilst other agencies and family/unpaid carers have been conceptualized into an initial model given some of the focused codes & categories that have related to these groups, comment was limited in richness; it is not known how further these roles could be explored, but it was felt that this would not represent a robust enough account to try to conceptualize them further.



Where overmedication sits within the role of the support worker, there appears to be a downward process of overmedication from services to the support worker, and then the support worker to the person with ID. Conversely; categories relating to reducing overmedication appears to work upwards from the person with ID to the support worker, and the support worker to services. This upwards and downward process of overmedication seems fitting with the implementation of power to those less privileged and bottom up actions of challenging this or being empowered against this power, as represented previously in the schematic of supporting care; providing care and receiving care.

The reciprocal roles therefor appear to represent a process, that can be more or less in one direction or another; imposition of overmedication from above, or resistance to overmedication from below;” Imposing and Resisting Overmedication”?

Appendix 12: Example of negative case analysis

P7 describes how her relationships with the clients as being central to her work, she does not however medication as playing a part in this role.

“for me it's about establishing a relationship with the customer, and the relationship is only is built from what you are, from what you can give or kind of thing isn't it. For me, observation the second one, you need to I mean if you are a new member of staff and you want my advice I would say, observe him, observe him and- and even if the person doesn't speak just communicate” (P7)

P5 describes his disillusionment in various care aspects of his role for someone with intellectual disability beyond that of medication administration.

“I'm just here to stop them. You know, help them with their personal needs you know, personal care, feed them and what have you, take them out really there. But I don't feel that I'm that much real, I don't see the benefit really, I don't get any job satisfaction” (P5)

P4 describes broader issues in negotiating his role with the people he supports where there is a disinvestment in the relationship between support worker and the person with intellectual disability due to wider factors.

“you got support staff that don't know the people they are supporting and you know- you know you've got services that are- that are taking on cases that they don't have capacity for so like just trying to- you know there's- there's like you know everyone's just trying to keep their head above the parapet so therefore kind of more, kind of you know just- just I think a lot of services are just trying to erm avoid cancelling sessions and they've got support staff that you know don't even realise that the guy's got epilepsy” (P4)

Negotiating Caregiving



It seems that the negotiating of roles between the support worker and person with intellectual disability cannot solely be represented in terms of psychotropic medication like with psychiatry and the care provider managers.

Appendix 13: Reflective diary entry example

Therapist in the research room

Throughout the first two interviews I have noticed how I struggle with the less structured format of formulating questions based on the experiences of the interviewee. Whilst wanting to get rich data and understanding of process, I found myself asking questions that may have forced the participant to answer in a certain way or to simply agree or not agree. This led to me struggling to find my words as I quickly tried to re-phrase my question halfway through asking it, sometimes with a degree of success... sometimes not as I had already asked as closed question to then immediately attempt to open it up again. It is in this where my experience of working clinically with staff and individual patients became apparent to me. Whilst my existing experience of clinical interviewing and psychological therapy has helped me to feel comfortable in the room and in understanding or eliciting emotion and experience in the interviewee, the drawback is how used to either giving interpretation, psychoeducation or facilitating a conversation with the direct expectation of change both from me and usually for the patient or their caregivers as well, as a research interview, this comes into conflict where there is not an expectation of some sense of improved wellbeing, most certainly I am not being commissioned to support the person to 'feel better' or for things to be 'better' no matter how subjective that is, it is apparent in the room and in the contract of therapy, whilst in research interviews, feeling better or having a meaningful moment is certainly possible, but as a researcher I have approached this person for my research needs rather than the interviewee approaching a service I am working in for help.

Appendix 14: Conventions used in transcribing audio data (adapted from Parker, 2005).

P: Participant (plus number in order of interviewing)

DW: Interviewer

[pause]: Pause in speech

(): explanation off text

[inaudible]: Unclear speech

-: interruption (either by self or by another, also indicates unfinished word)